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## ABSTRACT

This volume consists of a background discussion, coordinator's manual, and training manual dealing with developing programs for the in-home respite care (IHRC) of the developmentally disabled. Addressed in the background information unit are the nature of developmental disabilities; program variables, planning, and funding; and practical application in IHRC planning (legal issues, program planning and evaluation, grantsmanship, effective meetings, a respite care needs assessment survey, program costs and budgeting, and job descriptions and personnel interviewing). The program coordinator's manual deals with various steps in the IHRC program development process, including community resource evaluation, program philosophy, group presentations, establishing a communication system, fees, legal issues, recruiting respite care providers, recruiting consumer families, matching consumer families and providers, program administration, and followup. Covered in the training manual are general guidelines and suggestions, training program goals, planning the training sessions, observational guidelines, and the content of the training sessions (an overview of developmental disabilities; care provider and consumer family interview exercises; first aid and cardiopulmonary resuscitation; and information and exercises focused on seizures, medications, behavior modification, and program administration). Various handouts and forms are also provided.  
(MN)

# IN-HOME RESPITE CARE PROGRAM DEVELOPMENT

Background

Coordinator's Manual

Training Manual

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## **IN-HOME RESPITE CARE PROGRAM DEVELOPMENT**

### *Section 1*

#### **Background**

Introduction

What are Developmental Disabilities?

Trends in Service

A Continuum of Residential Care

Family Services

Respite Care

Home Respite Care

The plight of families who have severely handicapped members is beginning to be generally recognized. A service area that is emerging in response to these families' needs is in-home respite care. To understand the place that in-home respite care services can play in a continuum of community-based human services requires some general background information.

## *Section 1*

### **BACKGROUND INFORMATION**

#### **Introduction**

No one can accurately estimate the physical, emotional, and financial costs incurred by families who have a member who is developmentally disabled or severely handicapped. For these families, intensive support services become a necessity, not a luxury, if the family is to remain together and function as a unit. Many of the options and outlets which are routine to others, such as sitters (care providers), are difficult and often impossible to locate. These families must modify their lives so that a parent or family member is at home at all times to care for the family member with a handicap. Vacations are infrequent or impossible, and simple recreation such as going to a movie or out to dinner becomes a major event which must be carefully orchestrated. These families often find themselves overwhelmed with advice from family members, physicians, clergy, and friends. While advice may be well intended, it does not relieve any of the day-to-day stress. Increased levels of stress may lead to frustration, tension, marital discord, and denial of the problem on the part of family members. Families with a member who is developmentally disabled have had few options other than untold years of sacrifice.

The stress of families with a member who is developmentally disabled must be relieved, and relief can best be provided through a continuum of integrated community-based services. In-home respite care can play a vital role in this continuum. With a functional in-home respite care service available, families with a member who is handicapped may enjoy a more normal life and still assure good, constant care for the person with a developmental disability.

The information contained here is intended to help a community planning body determine if a respite care program is needed in their area and to give suggestions on how to organize such a program. Subsequent units of information in this volume deal with specific things an in-home respite care program coordinator will need to do



(Unit II: Operations Manual) and suggestions for training in-home respite care providers (Unit III: Provider Training).

Unit I, In-Home Respite Care: Program Development, deals with general background information such as the definition of developmental disabilities, trends in service, residential care, family services, respite care, and home respite services.

### **What are Developmental Disabilities?**

The most recent definition of developmental disability, provided in the Rehabilitation, Comprehensive Services, and Developmental Disabilities Amendments of 1978 (PL 95-602) characterizes it as a severe, chronic disability manifested before the age of 22 and involving substantial functional limitations in three or more areas (self-care, learning, economic self-sufficiency, self-direction, receptive and expressive language, mobility or capacity for independent living). The person's need for individually-planned services and multiple services for an extended time is also emphasized.

The definition should be interpreted in light of the disability's impact on the person's ability to perform chronological age appropriate functional skills in the natural environment under natural cues and consequences. Mental retardation, cerebral palsy, epilepsy and autism are the four diagnostic categories most commonly associated with developmental disabilities. However, osteogenesis imperfecta, spina bifida, muscular dystrophy, cystic fibrosis, and dyslexia are examples of some other specific diagnoses that might also fit the present definition. The definition is an attempt to get away from the exclusive use of diagnostic labels and to define common needs in terms of severe limitation in critical areas of life functioning.

### **Trends in Service**

Most handicapped persons, a majority of whom are only mildly handicapped, have always lived in their own homes and have gone to public schools. They may have been placed in special education classes but often "vanished" from view after graduation, apparently doing well enough to require no special service. Until the passage of the Education for All Handicapped Children Act (PL 94-142) in 1975, the families of members with developmental disabilities had few alternatives besides private or public residential facilities. With the passage of this law, schools were required to serve *all* handicapped children.

Public residential facilities (state schools) were first established in the U.S. in the mid-1800s, guided by a spirit of optimism about the capacity of the developmentally disabled or retarded children to respond to education and then return to the community. As these institutions grew, they began to move further and further away from their original habilitative purposes, largely because of pressures from various segments to keep retarded persons segregated (Wolfensberger, 1976). During the early 1900s, institutions became more custodial than habilitative in nature, and the residents were increasingly viewed as a social menace. Following World War II, however, new ideologies took shape. The developmental model of retardation (Roos, Patter-

son, & McCann, 1970) emphasized the potential of retarded children to continue developing in a stimulating environment and was a reaction against the medical model that had become entrenched in existing institutions. Normalization (Wolfensberger, 1972), another ideology, represented a critique of the dehumanizing conditions which had developed in large institutions and called for making available to retarded citizens the kinds of experiences and environments considered normal in society.

Perhaps the major outcomes of these new ideologies have been institutional reform and deinstitutionalization. Institutions for the retarded (which have always tended to serve the more severely retarded or developmentally disabled who cannot function well or are not wanted at home) have become more habilitative in orientation. But, because those residents with moderate and mild handicaps have been moved back to the community, the populations of these institutions have become still more severely and profoundly retarded, multi-handicapped or developmentally disabled. From 1850, when there were four public residential facilities in the country, until 1976, when there were 237, the number of institutions grew exponentially (Scheerenberger, 1976). The number continues to grow, but the facilities are becoming smaller. Since 1967, when the resident population reached a peak of 200,000, the institutionalized population has steadily declined to a current level of less than 150,000 (Scheerenberger, 1976, 1978).

Parallel to the decrease in institutionalized populations has been an increase in the number of smaller and more homelike community residential facilities. In a national survey, O'Connor (1976) was able to identify 611 community residential facilities for the developmentally disabled, most only recently opened. A survey (Bruininks, Hauber, & Kudla, 1980), which used a broader definition of such facilities and excluded only family or foster care arrangements and non-licensed facilities, found 4,427 community residential programs with a total population of 76,250. Over half of the facilities had opened between January 1973, and the time of the survey in June 1977.

The deinstitutionalization movement has been rapid, and community residential facilities today represent a major service delivery option for many retarded or developmentally disabled persons who are not capable of total independence. According to the survey of Bruininks, et al. (1980), approximately a third of the residents had come to their facilities from institutions, but almost as many (32.4%) had come from their natural homes. Thus, such facilities are also meeting needs among those who, while never institutionalized, require more training and support than their own families can provide. The remainder had entered their community residential facilities from other residential settings.

### **A Continuum of Residential Care**

In order to facilitate movement toward the most independent living situations and to meet the variety of individual needs, a continuum of care for people with developmental disabilities must be developed. Community residential facilities are an attempt to build in an option to fill the huge gap between living at home or independ-

ently and living in a large institution which provides many services which might not be needed for every individual.

On the continuum, institutions clearly represent the most "restrictive" model. They provide multiple services to those whose needs are most severe and who often require life-sustaining medical services as well as habilitation. Most of the community residential facilities developed thus far have been aimed at the moderately and mildly retarded who require fewer services and who are capable of greater independence. However, severely retarded persons are also being moved to community facilities. Community residential facilities differ widely from one another, ranging from "mini-institutions" to informally supervised apartments. Nursing homes, dormitories linked to sheltered workshops, halfway houses, and a wide range of group homes—some with live-in houseparent couples, others with shifts of staff—all qualify as community residential facilities. Some (e.g., halfway houses) are considered transitional in orientation and are designed to train residents to the point where they can move to more independent living arrangements. Others are intended from the start as long-term residences. Ideally, any community would have a range of options and would allow for movement of residents to less restrictive alternatives as they acquire greater independent living skills. For example, a developmentally disabled person might live in the natural family with the provision of in-home respite services until he reaches young adulthood, at which time he might obtain respite services in a group home. As an adult, he may move to the group home or halfway house for further training, then on to an apartment complex with a couple serving as supervisors, and finally on to an apartment with only occasional support and guidance from a visiting counselor or social worker.

About 62 percent of the residents of community residential facilities are 22 years old or older (Bruininks, Hauber, and Kudla, 1980), and the vast majority are in some productive activity in their communities. According to O'Connor's (1976) survey of community residential facilities, about 10% of the residents were competitively employed; 48% were in workshops or workshop training programs; 31% were in school, and 8% were in some other major day activity. Only 4% were without such major activities. These individuals, then, are active in the community and display widely different degrees of independence. Moreover, residents are drawing on the whole range of services available in the community, for it would be contrary to the purpose of small homelike facilities to have all services provided in-house as they are in large institutions.

### **Family Services**

In addition to these community residential facilities, a variety of family services has been explored both in and out of the home. These programs range from parent support groups to child management training which typically has a behavioral modification orientation. While a variety of services have been found effective, such services are typically developmental/demonstrative in nature, have temporary funding, and are not integrated into the ongoing community human service system. There would appear to be greater program emphasis on professionally controlled facility-oriented services versus consumer controlled in-home services. Our current human

service systems, social institutions, and resources are not oriented to support the integrity and natural environment of the family.

A trend towards greater support to parents who keep their children who are developmentally disabled at home is currently taking place. PL 94-142, which makes public schools available to all handicapped children and enriches the offerings of these schools, has certainly contributed and has made institutionalization necessary in fewer and fewer cases. Special federal and state legislation and consequent service program development, from the time of the Kennedy administration to the present day, have created a fabric of activity that sets the stage for effective action.

Most notable among these include the comprehensive mental health-mental retardation laws, the social security laws, the economic opportunity act, the rehabilitation act, the maternal and child health laws, the facilities construction laws, and the developmental disabilities act. The recent White House Conference on the Family (1980) has also drawn attention to the special needs of families with handicapped members and the importance of the family integrity. What might happen in the immediate future with the discussion of a "new Federalism," block funding, repealing of federal legislation and guidelines is uncertain, but in the present environment, one must work hard to remain optimistic.

### **Respite Care**

The most normal, independent, and least restrictive residential environment for any young person is with the natural family unit. However, when a family has no relief from the daily responsibility of caring for a family member with a developmental disability, no time for himself/herself, and no one to turn to in emergencies, frustration, isolation, and fatigue steadily mount. Temporary relief from caring for the family member with a developmental disability can enable family members to spend a relaxed evening away from home, keep appointments, attend meetings, or take a short vacation. Respite care provides a vital support to aid families in their attempt to retain a handicapped member in the family unit and should be a part of a community's human service system.

Respite care services were defined by HEW Social and Rehabilitation Services, Rehabilitation Services Administration, Division of Mental Retardation, as "Appropriate services, in a variety of settings, provided for the care of the mentally retarded person through temporary separation from his family, in or outside the home, for short, specified periods of time on a regular or intermittent basis, and involving other services as needed on an individual basis, for the purpose of relieving the family of his care in order to: 1) meet planned or emergency needs; 2) restore or maintain his physical and mental well being; 3) initiate training procedures in or out of the home" (Respite Care for the Retarded: An Interval of Relief for Families, 1972, p. 1).

Until recently, temporary care for the handicapped was generally available only through state institutions or when some of the various community programs set aside one or two beds for respite or short-term stays. Although community facilities and institutions continued to provide some temporary care to the handicapped, parents frequently appeared to use this respite care as "trial" placement. In a study of tem-

porary placements to several Texas state schools for the retarded, Cole (1970) reported that in two years, 54 (46%) of the 117 children were admitted as full-time in-patients. Community respite care is not as susceptible to being used as trial placement due to the limitations built into the length of service available.

Two recent studies have concluded that families of handicapped individuals in general prefer respite care provided in their home. Upshur's (1978) study of 339 families of handicapped persons in Massachusetts revealed that in-home respite care was preferred (57.8%), with community group homes (13.3%) being their second preference for overnight respite care. Moore (1977) also found that families preferred the same two options (68.2%) and (8.6%) respectively for short-term (day) care. Respite care in a state school/facility setting was only preferred by 0.6% for overnight and 0.9% for day care.

A needs assessment survey of families of handicapped individuals (Terraciano and Parham, 1980) found home respite care to be the most pressing need for these families. Of the families surveyed, 96% responded affirmatively to the use of home respite care if it were afforded them.

### **Home Respite Care Services**

In-home respite care has evolved because parents of the handicapped have found the options of institution or community group home respite care to be inadequate. In some cases parents "traded off" with each other to care for their handicapped children. In other instances, agencies were established or expanded to provide respite care within the home.

Within the home respite care service area, there are at least three distinct orientations (U.S. Department of HEW, 1972):

Homemaking services which were designed to bring a qualified, trained professional into the home to care for the person with severe handicaps and to supplement parent care and maintain the family unit.

Nursing services which are typically performed by a visiting nurse or public health nurses in the community. In addition to providing respite care, there is a heavy orientation toward parent training.

Qualified "baby-sitting services" which use groups of "sitters" trained to work with the severely handicapped and oriented toward providing home respite care services only. Initiated for the most part by parent groups, short-term in-service training about developmental disabilities are taught primarily by professionals.

In addition to the three orientations described above, there are three additional levels of care that should be considered:

Companion services which are most frequently used with adults who have developmental disabilities. An outside "peer" takes the handicapped family member to a movie, ball game, or other recreational activity, thus providing respite for the family. A counterpart for younger people with developmental disabilities would

be when a sitter/companion entertains the child with a handicap by working on an art project, playing a game, or taking the child to a play.

Foster home services are provided when someone takes the person with a handicap into his or her home rather than going into the client's home. This service orientation is perceived by some as more appropriately grouped in the "out-of-home" respite category. Even though the person who is disabled is not at home, the service is provided in a home setting, and the service is therefore appropriately placed under home respite care. Persons who provide this service require the same type of training as other respite care providers.

Care provider services provide short-term/in-service training for volunteers to serve as surrogate parents doing whatever is necessary for the DD person during the time they are in the home. The care provider would carry out, under the parents' directions, as normal a routine as possible, striving to maintain the physical, mental and social environment that the developmentally disabled or handicapped person is used to. This would include not only feeding, bathing, dressing, bedding and supervising the person who is developmentally disabled, but also maintaining the environment by cleaning, washing, cooking, and providing transportation or other activities normally performed by the family in support of the handicapped member.

These six home respite care orientations are not necessarily mutually exclusive or pure in their programmatic application. While you will frequently find homemaking services and nursing services operated in a singular, pure, multi-disciplinary manner by professionals with a heavier emphasis on family training than respite, the other orientations are frequently mixed. This mixed model approach, which utilizes sitter/companion or care provider services, depending on the needs and requests of the family, is grouped together under the general heading of In-Home Respite Care (IHRC). The foster home orientation, while frequently offered along with the other three, is not grouped within the IHRC area, in that technically it is not in the home of the person who is developmentally disabled, but in the home of the care provider. However, the sitter/companion foster home and care provider services mix works well, in that providing training to the highest level, the care provider service orientation enables a person to readily perform sitter/companion or foster home services also.

A diagram representing the overlapping nature of these services with the family is represented on the following page by a series of circles. The smaller circle represents the sitter orientation. Here the service is very similar to that provided by a baby-sitter to non-handicapped children. The person is not expected to perform household functions or serve in the parents' place. The parents will normally be readily available and merely out for a few hours to the movies, dinner, etc. This smaller circle represents the restricted scope of such services. The next larger circle represents the companion service orientation where the parent is again gone for a very short time and is more or less readily available. The companion provider will actively engage the handicapped person in social recreational functions, as opposed to merely "sitting." The next larger circle represents the scope of the care provider service where the normal and routine functions of the family are carried out in support of the develop-



mentally disabled person. Within this larger circle, the other two service orientations could take place in that the normal routine might call for sitting or companion types of activities along with the multitude of other functions. The larger and the last circle is indicative of the broader responsibilities of the parent/family as related to making decisions, providing direction, emotional, financial and other types of long-range and continuing support.

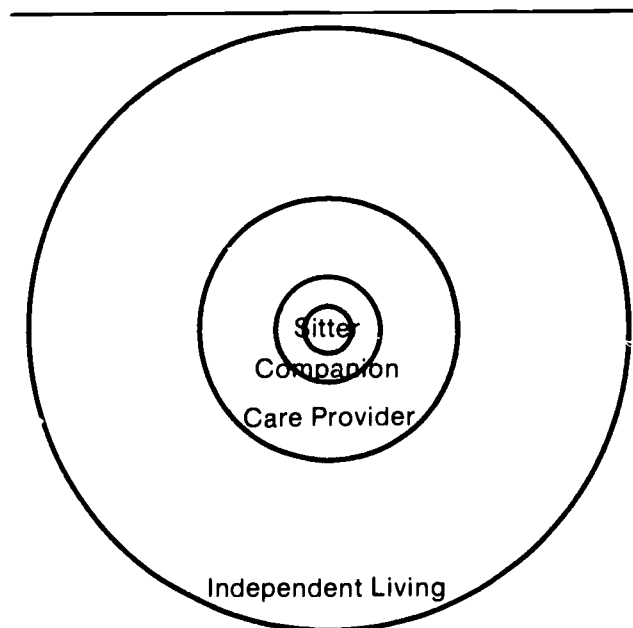


Figure 1. IRC Service Coverage

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This IHRC (in-home respite care) mixed model of sitter, companion, and care provider services would appear to be providing the largest measure of relief for families with severely handicapped members when other services are not required or available in the community (Respite Care for the Retarded, U.S. Department of HEW, 1972). This mixed service model for providing IHRC appears to have general and wide acceptance along with the high potential for cost benefit.

The most obvious benefit of this IHRC model is that the care and treatment of the handicapped person is provided in the home environment to which she or he is accustomed. Great anxiety and fear on the part of the handicapped person prior to or upon arrival for temporary institutional placement is a common reaction. Parents feel great guilt at "abandoning" their child in an institution. Community residential facility-provided respite may create many of the same feelings, but an IHRC program can lessen these reactions and provide both the handicapped individual and the parents with more benefits from their respite. Furthermore, since this IHRC model does not have a parent training component to it, the inference of parent inadequacy associated with other options is not present.

The home is considered by many experts to be the most productive, developmentally, educationally, and financially effective environment for the developmentally disabled individual. IHRC can assist families of the handicapped in providing quality care. Without some measure of relief, the family environment may gradually deteriorate as family members become "burned out" and discouraged.

In diagram or schematic form, the various respite care options might be represented as presented below.

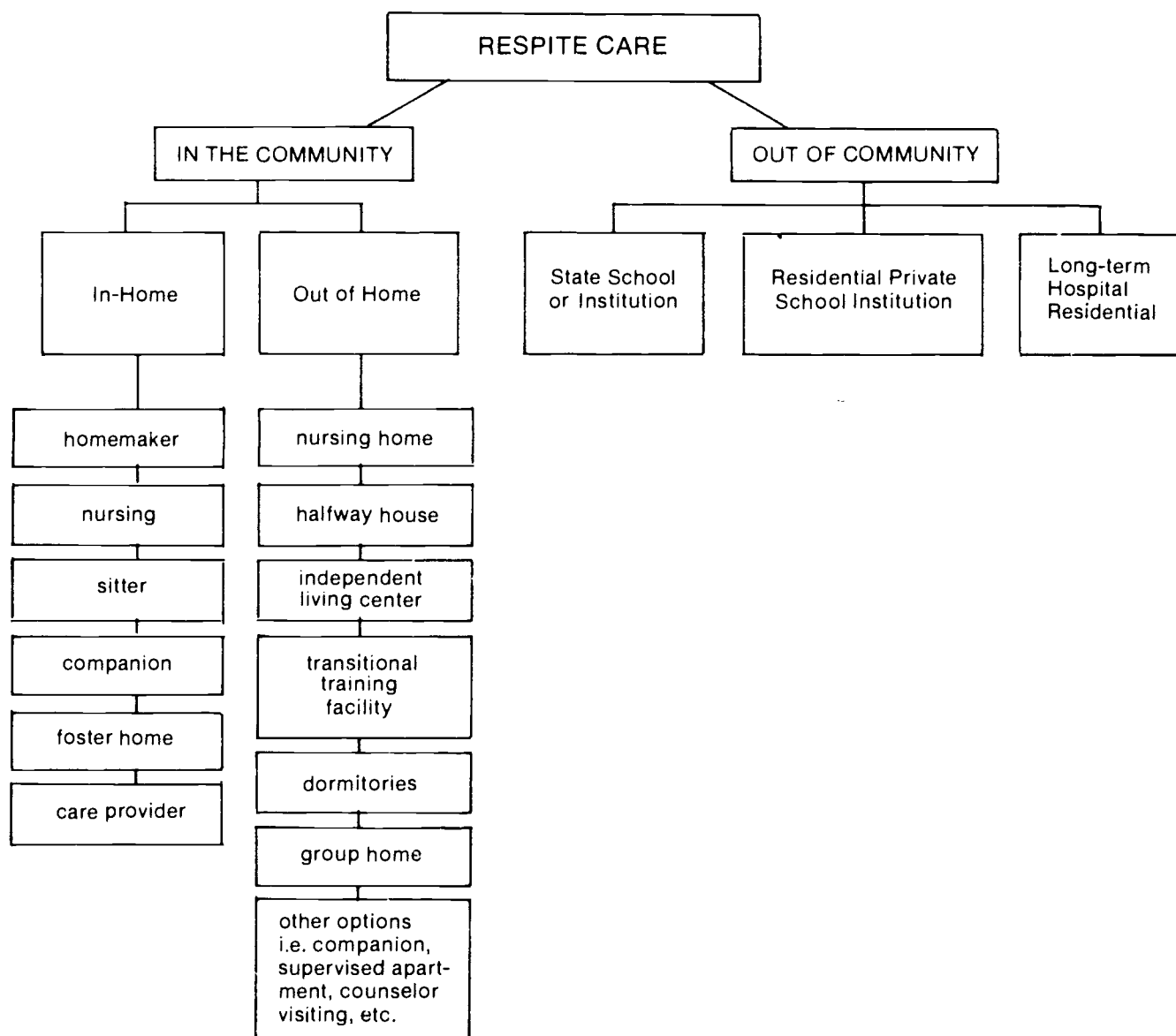


Figure 2. Respite Care Options



## IN-HOME RESPITE CARE PROGRAM DEVELOPMENT

### *Section 2*

### **Program Variables, Planning and Funding**

Introduction

In-Home Respite Care Program Variables

Community Planning Principles

Funding and Grantsmanship

Making informed decisions regarding program development requires considerable knowledge of program variables. This is true for in-home respite care service as well. The major variables related to in-home respite care are presented in this section. In order to conduct sound program development, one must have a good understanding of community planning principles. This section enumerates some of the major principles related to community planning. Once program variables and community planning are in place, sound funding must be sought. Because funding for human services frequently comes from grants or contracts, these processes are explained.

## *Section 2*

### **PROGRAM VARIABLES, PLANNING, AND FUNDING**

Thus far background information has been presented with the hope that the information would help you recognize the needs and benefits of an in-home respite care program for your community. Section 2 deals with questions related to various program options which planners will need in order to make decisions about establishing an in-home respite care service. Specific techniques and procedures for community planning are provided as well as some information and suggestions on funding and grant writing.

#### **In-Home Respite Care Program Variables**

Because the concept of respite care is relatively new, no universal model exists, and very little research is available. There is no "one" program package which will be successful in every community but observations by staff of the Research and Training Center in Mental Retardation at Texas Tech University of various programs throughout the United States have helped to form some strong suggestions about the organization of respite care programs. The following are variables which are most important to the organization and operation of an effective program and are considerations which will be faced by virtually every community attempting to establish an in-home respite care service.

These eight areas are some of the major variables which we have observed in programs, and they need to be considered during the initial planning.

#### **1. The Program Coordinator**

One of the most important variables in an IHRC service program is the coordinator (director) of the program. The director is responsible for recruiting clients and pro-

viders, training providers, providing public relations, and a variety of other jobs. Selecting and employing the right person to fill this job may indeed be the most important step in the successful implementation and continuation of an effective program. Most of the coordinators we have met were experienced, trained human service professionals. This experience and training, when combined with sensitivity, organizational ability, and good interpersonal relation skills, appears to be the key factor of the coordinator's role. We cannot stress strongly enough the necessity for careful consideration of the person to fill this position. A strong coordinator will direct and maintain a strong IHRC program.

## **2. Program Affiliation**

An in-home respite care program, if at all possible, should be affiliated with an existing agency which has credibility in the community as well as interest, concern, and commitment to assisting in the development of IHRC services. Consider such agencies as local affiliates of the Association of Retarded Citizens, United Cerebral Palsy, National Epilepsy Foundation, and other consumer-oriented organizations or local mental health/mental retardation centers, county departments of human services, and community rehabilitation centers. The two common factors which we observed were that all of the agencies housing IHRC programs were oriented toward human service delivery and were locally administered. Affiliation with such an agency should be carefully considered. While such a connection can facilitate funding, community contacts, and the credibility of an IHRC program, your choice should be an agency which is strong in the community, has been successful with its existing programs, and one which will benefit you in your affiliation.

## **3. Clients**

Another key factor in designing respite care services is the type of client which the program will serve. Consideration should be given to types of disability, severity of disability, age, sex, residency and the geographic location of the client. Frequently a funding source may dictate what clients should be served. If multiple funding is obtained, more latitude can be exercised by the program. If there are any particular types or classes of handicaps that will NOT be served, such as clients with life-threatening health problems, these exceptions should be explicitly named before publicizing the program.

## **4. Providers**

Finding the right care providers for the program is essential. Frequently the types of providers that are obtained will relate directly to those sources which are used in recruiting. For example, some programs' reliance has been placed almost exclusively on college students. Other programs have gone to religious groups, social groups, groups of senior citizens, etc., for recruiting. If variables such as age, sex, and other background elements are important to your community, you should seek people who are representative of these factors.

Terraciano & Parham (1930) found that most parents show a preference for female adults in good health to serve as respite providers, but a variety of providers (age, sex, race, etc.) will be most beneficial for your program. Unit II will deal in depth with methods of recruiting providers.

## **5. Training**

Training is another key variable to home respite care programs. The training of the service provider is dealt with extensively in Unit III of this volume. Training will also be needed for the core planning or advisory group, staff, families, and other agencies and professionals as well. Some of these training needs are addressed in the Operations Manual (Unit II) under such areas as recruiting, public education, coordinating, communicating, reporting, and recording.

## **6. Liability**

The issue of liability in respite care programs has been dealt with by various programs in a number of ways. Some programs report only the matching of providers and clients and not employing the providers with the intent to avoid liability, while other agencies want to be the employer in order to have agency liability coverage. In some other cases, programs have reported that their providers are considered only to be volunteers, thus avoiding the liability issue. It would appear that at the present, there is no clear law or litigation related to liability in the IHRC program area. However, a review of some current legal components of this issue is presented in Appendix A of this unit.

## **7. Financial Considerations**

A large number of program variables can be grouped under "program finances." For example, the issue of how much to pay respite providers and what portion of the wage is paid by whom are key questions. In virtually all programs now operating, there is some type of sliding scale whereby a family who can afford to do so pays for at least part of the cost for the service (Figure A, p. 1.80). Nearly every program now operating also pays something to the care provider, and this wage usually approximates the minimum wage. However, in some programs, wages were as little as fifty cents an hour, while others were as much as \$3.50 per hour. Some programs have espoused a philosophy of volunteerism, with a volunteer fee of fifty cents an hour paid to providers. Successful programs have been operating on both ends of this wage scale.

Another variable related to cost and wage is how many hours of subsidized respite care a program will support. The best way to set budgetary limits on programs appears to be in the matter of the length of time a subsidy will be paid. It is a variable that must be considered carefully when planning your program.

Other costs such as transportation, mileage, staff salary, office expenses, training expenses, and utilities are a part of all program budget considerations and will vary from program to program. (See also Section 3 and Appendix F.).

## **8. Funding**

Funding is a principal concern for all programs, especially when a new program or the expansion of an existing program is involved. In-home respite care programs have been funded by a variety of sources such as the Office of Developmental Disabilities Administration on Aging, Department of Human Resources, comprehensive Mental Health/Mental Retardation funds, and specifically appropriated state funds. Funding information is of such a major concern that it is dealt with in more depth later in this section. At this point, it will suffice to say that stable, long-term funding sources are desirable, and multiple-funding sources are preferred.

These eight areas are some of the major variables which we have observed in programs, and they need to be considered during the initial planning. There are also several other variables which must be dealt with as a program begins to serve clients. Questions such as, how does a family go about requesting services, what emergency and back-up procedures are there, etc., are dealt with in the Operations Manual. The major considerations given here are those variables that one would want to consider when planning to initiate an IHRC program.

### **Community Planning Principles**

A number of general principles have been developed from successful community planning efforts and will be presented here. In the process of developing an IHRC program, one is encouraged to approach the planning effort in a way that will use a comprehensive, integrated service delivery system.

- a. Program or community planning efforts begin with some individuals or groups within or outside the community who perceive the need for such planning and follow through with a commitment to doing something about the need. (David, Gallagher and Wilson, 1978)
- b. No one individual or group within or outside the community has a comprehensive perspective of the total need for services (Davis, et al., 1978).
- c. While general planning might be possible on a community -wide basis, goals must be reasonably tight for specific programmatic planning (Parham, 1979).
- d. Outside consultation in a planning effort can provide experience not otherwise available, but ownership of a proposed program must be maintained in the community itself.
- e. If outside consultation is utilized, it should be as a facilitator and information source. To fulfill this role, consultants must have the freedom to negotiate with different subgroups in the community in order to formulate a coalition.
- f. A community planning effort should be carried out by a team which includes representatives from the following key community groups: service providers, service receivers, community decision makers, the general public and/or third party consultant facilitators.

- g. Neutral leadership, which is free from suspicion regarding selfish motivation and has credibility with service providers, consumers, and other elements of the community, is more capable of pulling together various components of a community plan than a service provider alone might be. Having some neutral members who are not affiliated with any one agency can facilitate the group planning process and provide a client-oriented model for effective planning. This neutral leadership might be represented by the consumer segment, professionals whose agencies are not directly involved in the particular service area, or others. When such individuals can be identified, they should be consulted prior to all major decisions and incorporated into the power structure.
- h. Each community is unique and the plan developed for that community should be its own. The temptation to adopt totally a plan developed for some other community, to have an outside planner do all the planning, or to permit funding sources to impose a plan should be resisted. Those involved in community planning are often tempted to rush out seeking funding and to tailor their programs to meet the funding requirements of a particular source. Local needs and services often do not match the outsiders' program designs.
- i. The joint community planning process itself may be the single most important element in facilitating program growth and change.
- j. For a community plan to succeed, there must be a strong commitment on the part of all parties to make it work.
- k. Consensus on the organizational structure and a strong commitment to make it work are more important than any of the specifics related to the organizational structure.
- l. When communication, input, and consensus are continuously sought, the process of grant development can prove helpful in consolidating organizational structure and confirming commitments.

Today's trend in agency operations is toward multiple funding and referral sources (Parham and Wainwright, 1978). However, as mentioned earlier, the temptation to rush out seeking funds and tailoring a program to meet particular funding requirements should be avoided. The emphasis should be placed on planning for local needs and making the planning process work.

Representatives from each segment of the community have information to give that only they can provide. For example, parents are the only experts available on the problems their particular families face, psychological or professional interpretation aside. The task of information gathering through community needs surveys has an essential by-product; constituencies are formed which cut across individual group or agency boundaries and focus on the unmet needs and shared commitment of resolving issues. Regardless of the solution ultimately chosen, the process itself produces a better informed, mutually committed group of individuals who begin to communicate more openly with each other, share resources, facilitate client movement, hold each other accountable, and in general, work together more effectively. The process of planning for a community in-home respite care service can proceed in an orderly,

beneficial manner and result in a number of valuable spin-offs. (See Appendix B for additional information on program planning.)

### **Funding and Grantsmanship**

Once you have developed an IHRC program plan through your community planning effort—outlining strengths, needs, goals, objectives, strategies, and evaluation procedures—how will you fund its implementation? In some cases, the agency chosen to implement in-home respite care services might have staff and dollar resources that could be reallocated to implement the plan, or perhaps the agency could establish a purchase of services agreement with someone else to provide the new services. In many instances, however, the agency may choose to seek outside funding in the form of a grant or contract.

Distribution of funds to worthy causes through grants and contracts has evolved into a complex system involving constitutional law, state and federal legislation, accountability, management, and administration (Willner and Hendricks, 1972). Today, the use of grants and the art of grantsmanship require a working knowledge of federal and state grants as well as corporate and private giving. Many institutions, both profit and nonprofit, private and governmental, have an interest in development of resources for their program. Almost all need more funding support, and for some, grants are the only means of existence.

With the passage of enabling legislation in the 50s and 60s, federal rather than private monies have taken over funding for human service programs. Since then, hundreds of federal granting agencies have been established to distribute the tax monies for public and private causes. Congress annually authorizes and appropriates approximately \$56 billion in grants and contracts to be awarded by more than 400 agencies. The major departments that administer funds that may potentially be used for IHRC programs are the Departments of Health and Human Services, the Department of Education, and the Department of Labor. Specific programs within those departments that deserve special attention are the Administration on Developmental Disabilities and its state counterparts, the Administration on Aging and its local authorities, Child Welfare Services and their state and local counterparts, especially Title IV and XX of the Social Security Act (PL 96-272), Child and Maternal Health Services and its state departments of health, Social Security Administration and its local and state counterparts, Rehabilitation Services Administration and its state agency and local offices, especially Title VII—Comprehensive Services for Independent Living (PL 95-602), and Special Education with its state and local programs under PL 94-142. There may also be some potential support from other federal departments such as Housing and Urban Development and the Department of Agriculture with some of its home services to rural areas. It is extremely important to devise and execute ways to take advantage of funds already available through these federal systems.

For a potential grantee to be successful in applying to a federal or state agency for support, the organization must examine carefully any pertinent information about the agency's history, traditional funding patterns, and the current climate for funding. An obvious method of analyzing the federal grant picture is to look at federal agencies'



annual budget requests to Congress. One can then analyze actual appropriations made to programs for which his or her organization is an eligible applicant, keeping in mind that there is a scramble by federal agencies at the end of the year to encumber their full appropriation so that funding levels will not be scaled down the following year.

As a result of evolving federal tax laws and a desire by private philanthropists to maintain control over their giving, more than 26,000 private foundations and charitable trusts also have been established. Foundations today distribute approximately \$30 billion annually. Under current tax laws, foundations must pay out not less than 5% of their assets each year. There are various kinds of foundations including general purpose, special purpose, family, community and corporate. Each has its own history and unique objectives. In the past five years corporate foundations (large industries) have shown the greatest increase in funds.

Every organization that solicits grant support should have a comprehensive grant resource reference library. These materials should be indexed and easily accessible to potential project investigators. A suggested resource list with descriptions of useful publications and information on how to obtain them is provided in Appendix B.

Applications for federal and state support are available through both grants and contracts. Basically, a grant consists of funding for what an organization would like to accomplish, whereas a contract consists of money to carry out projects that the funding source deems important. Although the grant has been the traditional funding mechanism used by the federal and state government since the early sixties, an increasing amount of funding is currently being distributed through contracts. This federal involvement has made it increasingly important for one to also be a competent contract administrator.

A typical grant application requires a long lead time to allow for processing through local, state, and federal systems. A contract, on the other hand, is a bilateral agreement between a contracting agency and a principle investigator. It requires much less red tape and review and is therefore much easier for federal and state funding agencies to administer. As a result, funding agencies are now increasingly utilizing the contract, in lieu of the grant, to distribute funds.

A potential grantee should never ask "Where is there funding available?" without first asking "What are our needs?" To apply for funding simply because it is available usually creates rising costs for services and often does not satisfy the real needs, even when money is received.

One of the best approaches to needs identification is the community planning process previously outlined. Through the community planning process, identification of needs as well as resources can be made, and a plan outlining goals, objectives, strategies, costs and evaluation procedures can be developed. If local, ongoing, currently existing funds can be allocated to the implementation of an IHRC program, this would be preferable. If, after careful analysis, it is the consensus of the planning group that outside funding must be sought, an application to potential funding sources must then be developed. In virtually all applications for funding, a proposal



narrative is required. The proposal narrative is where the idea must be sold in concise, easy-to-understand language. It should include at least the following topical subheadings for logical presentation and rapid cross reference:

1. *Statement of Need.* Identify the problems or opportunities to which the project will be addressed, i.e., in-home respite care services. To demonstrate commitment, explain what, if anything, your agency is already doing about the need or opportunity. Show that you are aware of what other individuals, organizations and agencies are doing and relate it to what you propose to do. Results of a literature search should always be included. In some cases a needs assessment can be helpful as well.
2. *Client group or beneficiary.* Define the client or other beneficiary groups with which project personnel would be working. Explain how this group has been involved in planning the project, in identifying needs and in setting objectives. Tell how many persons will be involved in the proposed program.
3. *Plan of action.* A plan of action frequently is developed by the community planning group and would include at least four components—goals, objectives, strategies and evaluation. *Goals* state the general direction of the plan or project, *objectives* specify behavioral outcome-oriented, time-link steps toward reaching a goal. *Strategies* outline steps toward reaching an objective, i.e., they tell what procedures will be used, how they will be implemented, who will carry them out, and where and when they will take place. *Evaluation* determines whether the strategies are carried out and the objectives are met.

For more detailed information on program planning, you are referred to Appendix B of this Unit.

In addition to the narrative, most grant applications include specific forms and information. For example, most require budget information on their form and frequently have some type of matching formula. Most funding sources also have categorical limitations such as disability and age of clientele to be served. While most funding sources have their own priorities, they also respond favorably to innovative ideas and well-developed proposals. Perhaps the most crucial aspect of the proposal is developing sound objectives that can be observed and measured.

Most funding sources want the same information, but each will have its own format for requesting the data. Keep in mind these do's and don'ts in planning and developing grant applications (England, 1978):

1. Learn all you can about the funding source, its present concerns, and whether or not the source would be interested in your project.
2. Ensure that your proposed project is needed and that you are not simply applying because "the money is there."
3. If applying to more than one source, make sure each presentation is tailored to the requirements of the particular grantor.
4. Enlist the help of your colleagues, and for a federal grant, be sure to contact your federal regional consultants for assistance.

5. Avoid personal pronouns and present your project in terms of services to the community.
6. Develop a well-constructed evaluation component. If the evaluation procedure is inadequate, it could kill the proposal quickly.
7. Meet all submission deadlines.
8. Do not attempt to use political influence to sway the awarding of grants unless you can document inadequate review or preferential treatment toward other grantees.
9. Do not try to bypass established channels.

If your IHRC proposal is funded, remember these two additional principles:

10. Do not accept funding if you cannot meet the terms and conditions of the grant.
11. Ensure that all records are kept in accordance with the grantor's guidelines and that all expenditures can be justified and documented.

## IN-HOME RESPITE CARE PROGRAM DEVELOPMENT

### *Section 3*

#### **Practical Application in IHRC Planning**

Introduction

Core Planning Group Selection & First Meeting

Second Core Planning Group Meeting

Third Core Planning Group Meeting

Summary & Follow through

In the two preceding sections, you were required to read and to process information but not take any specific action. At this point, specific actions are called for. A Core Planning Group will be selected and brought together for at least three planning sessions. Additional specific information that the planning team will utilize in performing their planning tasks is presented. Planning tasks are enumerated with fill-in-the-blank type of recording to follow discussion and the gathering of information between planning sessions. This Section will culminate in the development of a community-based plan for in-home respite care services and the hiring of a coordinator for implementation of a program.

### *Section 3*

## **PRACTICAL APPLICATION**

### **Introduction**

In this section you will be exploring the possibility of establishing an IHRC program for your community. Using the background information presented earlier in the unit, you will now want to form a Core Planning Group and jointly make some decisions regarding IHRC services.

Because of your interest in this information, it is assumed that you are willing to accept some of the leadership roles in formulating a core planning group and initiating the planning process. To do this, there are some very basic steps that should be taken. To help you think through the process, critical information and specific steps that need to be taken will be enumerated and outlined on the following pages.

### **Suggestions for Effective Meetings**

The first core planning group meeting needs to be set up and extra planning time taken to ensure that the meeting goes well. Meetings are generally scheduled for the purpose of sharing and clarifying information. Often too little effort is devoted to planning the meeting details. Expected outcomes of meetings can vary; however, the basic elements for effective meetings are essential. Particular attention to pre- and post-meeting activity is vital. Meeting planners need to be sensitive in selecting the proper format for various types of meetings to insure productive and meaningful results for all in attendance. Four common meeting formats are given in Figure 3 (p. 1.27).

### **Starting an In-Home Respite Care Program**

To proceed from recognition of the need for in-home respite care services in your community to having a quality program will call for a good deal of work on the part of

a number of individuals. In regard to the different types of meetings just outlined, the first meeting you will call will be a Basic Information type A. The core planning group would probably then move into a second meeting of a problem-solving and/or program-development nature and eventually into a third or fourth meeting to finalize an In-Home Respite Care Program Plan and to initiate the program by hiring a program coordinator. The Skilled Development type D meeting would be the training that you would provide for respite providers. (Unit III deals specifically with this aspect of an IHRC program.)

As noted in Figure 3, the Basic Information meeting would require a chairperson. The person chosen to chair the meeting should be someone who has shown an interest in the program and who has good organizational skills. If you feel that sufficient contact and planning preceded your utilizing this information, then the Basic Information Meeting may be skipped, and you would want to set up a format type B, Problem Solving meeting. The format which would be most appropriate for you to use in your community is left to your judgment, but in either case it needs to be carefully planned. Therefore, you should carefully review all of the information provided here regarding a first meeting and become familiar with the contents of this In-Home Respite Care Manual. The review of information on the first meeting will help you decide what type of meeting is best for your group/area/community. Reviewing the entire manual will help you work out long-range plans and be more responsive to questions during the initial meeting.

# PROJECT WORK PLAN

## OBJECTIVE

## STRATEGIES

## EVALUATION

Figure 3  
MEETING FORMATS

	A	B	C	D
Meeting Elements	Base Information	Problem Solving	Program Development	Skill Development
1. Leadership	Chairperson required Consultants-Group	Chairperson required	Chairperson and consultants optional	Consultants or Resource Person required.
2. Size	Generally unlimited	8-15	8-15	25-35
3. Time	30-40 minutes	2-3 hours (Open)	Open	2-3 hours (Open)
4. Participation	Participants generally listeners	Participants active	Participants active	Participants active
5. Facilities	Chalkboard, over- head projector or newsprint, other visuals.	Chalkboard, over- head projector or newsprint, other visuals, refer- ences, writing materials, etc.	Chalkboard, over- head projector, or newsprint, other visuals, references, writing materials, etc.	Depends on type of skill, e.g., VTR, etc.
	Traditional trans- mitter/receiver relationship	Brainstorming Delphi-1-3-6 subgrouping, etc. Phasing— 1. Clarify problem 2. Generate ideas for alternatives 3. Individually assess ideas/rank order 4. Reach conclusion	Independent work small group inter- action/sharing/ comparing/creating	Workshop/seminars/ independent work/ small group inter- action experiences to actualize skill or apply knowledge

## Setting up the First Meeting

The next series of information deals with setting up your first core planning meeting. Review this information ahead of time so that you, the leader, can comfortably lead the group through this initial planning process. If you are not familiar with setting up and conducting meetings, you should refer to the information in Appendix D (Outline for Effective Meetings).

**1. Selection of core group planning members:**

This group should be kept reasonably small (7-9 persons is about right) but have representation from at least the following areas: (a) family/consumers; (b) agency/programs currently providing residential/respite services; (c) potential referral and funding sources. Below, fill in the names and affiliations for a potential core planning group. Try to get broad representation from high-level administrative personnel who would be interested in getting directly involved with in-home respite care service.

[illegible]

2. Contact the individuals noted above and set the time and place for the first meeting. Be as accommodating as you can with the meeting time and place. If some of the key people cannot make the meeting, see if they will send representatives. For the first meeting, inform the people that you are "seeking their ideas about the need for an in-home respite care service in the community, and how the need might be met."

Meeting date: \_\_\_\_\_

Meeting time: \_\_\_\_\_

Meeting place: \_\_\_\_\_

Individuals committed to attend:

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3. Frequently, planners feel left out if they don't have all the information that the leader has. Whether or not this information is provided may be contingent on factors such as how familiar the persons are with home respite care services, community planning, needs assessment, the establishment of goals/objectives, and grant proposals in initiation of new services. If you feel that they would prefer to have the same information that you do or that they have minimal knowledge and information in these areas, you may wish to copy selected portions of the information in Sections 1 and 2, or you may wish to order additional copies of the In-Home Respite Care Volume.

\_\_\_\_\_Information not necessary

\_\_\_\_\_Information would be helpful and have contacted the following individuals concerning the following subjects:

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**INSTRUCTIONS:** To make the meeting go more smoothly and more productively, I would appreciate it if we all could do the following beforehand:

Read and become familiar with sections 1 and 2 of the enclosure.

Ask colleagues what they know about In-Home Respite Care Services and what is currently being provided in the community; come prepared to share that information.

Think about what your personal commitment to In-Home Respite Care Services for your community is and how you can contribute.

I appreciate your willingness to work on this committee. I believe that In-Home Respite Care Service is something that is badly needed in our community and that you have something to offer from your particular perspective that can be helpful in organizing such services. I look forward to seeing you, and if you have any questions please let me know.

5. Based on your knowledge of the community and previous studies, you may or may not need to conduct a needs survey for in-home respite care services. However, it is likely that one of the greatest points of discussion during your first meeting will be the need for additional information regarding in-home respite care services. Therefore, the following information on needs assessment is provided.

You should review this beforehand so that you can be informed and, if needed, share during the first planning meeting guidelines on conducting a needs assessment. If you know that no information in this area exists and that development of such data will be necessary for program and/or grant development, you may wish to provide the group a rough draft copy of a needs assessment survey form. (Information on Respite Care Needs Assessment Survey can be found in Appendix E.)

6. You are now ready for the first meeting. Select a comfortable room for the meeting with conference table and chairs, if possible. Have refreshments prepared and serve them as the people arrive to help set a relaxed atmosphere.

Start the meeting by making sure everyone has met. Have everyone give their name and affiliation or reason for being interested in home respite care services.

After the introductions, open the meeting by briefly restating the purpose for the meeting. At this point, it is a good idea to have additional copies of the agenda to pass out in case anyone did not bring theirs with them. Having carefully thought through the agenda, you will want to try to follow it as closely as possible. This includes starting and stopping on time as well as covering all of the major points.

After making sure that everyone received the enclosure(s), briefly review sections 1 and 2 of this Unit for the group. You should not take more than five or ten minutes for this. Space is provided here for making notes and outlining your comments.

Notes: \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

7. Follow the agenda as written working through each item and striving to stay on time. Give all group members an opportunity to contribute and solicit specific information from those who may not be participating as actively as others. See that no one person, including yourself, dominates the discussion.

Space is provided below to make notes and record information so that you can write up minutes for the meeting.

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[illegible]

**SECOND CORE PLANNING MEETING:** Time\_\_\_\_\_

Place\_\_\_\_\_

Date\_\_\_\_\_

Following the meeting, check Phase VII, Meeting Records, and Phase III, Commitments and Criteria, for success as specified in the Outline for Effective Meeting, (Appendix D) to assure proper follow-up of the meeting.

## **Second Core Planning Meeting: Program Development**

Careful planning of the first meeting will result in an effective and productive meeting. You will have begun to develop a committed group of planners who will be motivated to follow through and help establish an IHRC for your community. Write up the proceedings of the first meeting and send them out with agenda for the second meeting. Expect the group to come to the next meeting on time, at the scheduled place, with their information well organized. Facilitate the follow-through and commitment of others by being well organized with your own tasks.

The second meeting of the group should be oriented toward Format B, Problem Solving, or C, Program Development. If things moved slowly during the first meeting, you may need to do some additional problem-solving activities. However, if the meeting went well, the group may be ready to move into a program-development meeting. Frequently, these specific types of formats are not pure in their design and may be a mixture of the two. At any rate, you should be the person who is in the best position to know whether or not the group is ready to move on to a specific program development or if they need to do some additional problem-solving activities. Our assumption here will be that the group is ready to deal with program development activities.

Review the Program Development Outline in Table 3 to refresh your memory if you are not familiar with program development (i.e., the development of goals, objectives and/or grant applications) and how to work with small groups. An outside consultant might prove to be very helpful at this stage of community planning. The information on Program Planning found in Appendix B and the information in Section 2 of this Unit should prove very helpful for this Core Planning Group meeting.

The meeting should be no longer than three hours. Schedule refreshment breaks of 15 minutes or less at hourly intervals. Visual aids, such as a chalkboard, charts or other instruments where group work can be easily displayed, are frequently helpful. Group techniques such as the processes for establishing priorities for goals and objectives may also be helpful. Review the information that follows in this section in order to defer questions that will be dealt with in later materials.

The following suggestions and examples are given as guidance, but your program may differ substantially. The important thing is that a program is developed to meet your community needs.

### **Outline for Second Meeting—Program Development**

1. Follow procedures used in the first meeting, including the use of a written agenda.
2. Begin the second meeting by summarizing the first meeting, and setting some expectations for the current meeting ( i.e., utilizing information developed since the last meeting in order to develop a program plan for in-home respite care services in your community).

(Notes for opening expectations and major points:)

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Make your opening comments brief and, in turn, encourage others to keep their comments brief and to the point.

3. Call on those who had specific assignments from the first meeting to present reports. Use charts or chalkboard to record if this would be helpful.

Person	Assignment	Results

4. Following the reports, make summary statements and see if the Core Planning Group has reached a consensus as to their commitment for an in-home respite care program. Based on this consensus for program development, try to develop a brief statement of need (see Section 2, p. 1.20, I. *Statement of Need*).

Statement of Need: \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

5. After reaching consensus on a brief statement of need, solicit ideas from the group on defining who the client (s), group (s), or beneficiary (ies) of the in-home respite care program will be. This would probably include not only the handicapped persons, their families and the community at large, but also those individuals who receive training as respite providers and provide the service (see Section 2, p. 1.14).

Client, group or beneficiary: \_\_\_\_\_

\_\_\_\_\_

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6. Having reached consensus on a needs statement and the client or beneficiary group(s), move into more specific planning for an in-home respite care program. To develop a plan of action to establish the program, we suggest a conceptual model, the essential elements of which include goals, objectives, strategies and evaluations (see Appendix B).

The strengths of your community and the need to establish an in-home respite care program developed during the first meeting, along with all other data and discussions, should serve as a good foundation for the planning that follows. If you have completed the development of a needs statement, the development of a goal for the overall program will be easy. However, stating more specific behavioral outcome-oriented objectives will probably be more difficult and call for more discussion.

On the following page is an example of a project work plan; a suggested format for recording your plan can be found on the page following the example.

7. Probably cost and money have been discussed on a number of occasions, but actual budget development should be deferred to this point. After developing goals, objectives, strategies and evaluation procedures, the core planning group should consider some of the major variables related to budget development and funding. A suggested budget outline is given below (also in Appendix F), and notes available resources and funding needed. When developing the budget, you should consider not only the various cost factors but, to the extent possible, the resources currently available, additional resources that will be needed, and where resources might be sought. For example, the agency housing the in-home respite care program may be able to provide office space, equipment, furniture, utilities, and telephone. If so, these expenses should be listed as funding available, with an estimated fair market value placed on them.

Position(s)	Percent of Time	Funding Available	Funding Needed
Project Director	_____	_____	_____
Program Coordinator	_____	_____	_____
Secretary	_____	_____	_____
Consultant Services	_____	_____	_____
Travel	_____	_____	_____
Equipment	_____	_____	_____
Supplies	_____	_____	_____
Other	_____	_____	_____

8. Once the core planning team has developed this outline for a program plan, you will want to make sure they have considered the major variables in establishing an in-home respite care program. While you should solicit group input concerning all of the major variables, the actual development of a program plan and budget is best done by a single person. As a checklist on the major variables, you should note the following. (These variables are discussed on pages 1.13-1.16)

- a. Agency affiliation: Where is the best place for the in-home respite care program to be located?

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- b. Clients and providers: What restrictions, if any, will there be?

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- c. Provider training: What type and who will provide training?

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- d. Liability and legal issues: What legal and liability questions need to be addressed?

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- e. Program cost and funding: Has enough information been generated to develop a detailed budget and/or grant proposal?

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- f. Program coordinator: What requirements are necessary and which are desirable?

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- g. Other:

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9. At this point, if there has been sufficient discussion, information, and input from the core planning group, someone could begin to write a program plan. The most logical individual to write the plan would be a high-level administrative person from the agency within which the in-home respite care program would be placed. You may be this person, or you may wish to assist this person, but for purposes of writing such a plan, a single individual is typically designated as writer even if he or she works with a small group.

A few essential outcomes of this meeting would include: designating a writer for the program plan; establishing a timetable as to when the plan could be reviewed by the core planning group; and arranging a meeting time to carry out any needed action, such as approving the plan, applying for funding, or hiring a coordinator.

\_\_\_\_\_ will write the plan by \_\_\_\_\_, and the core planning group will receive the written plan for review by \_\_\_\_\_.

The core planning group will meet again on \_\_\_\_\_ at \_\_\_\_\_ to review and approve the program plan and to carry out the plan or other needed action.

### **Third Meeting Core Planning Group: Program Development/Initiation**

If your first two meetings have gone well, you should have established a core planning group and a program plan. This program plan would have been sent to committee members for review. The third meeting is called to review and to follow up on the program plan. In addition to specifying who will carry out any additional action, you will want to consider other things such as funding and/or hiring of a coordinator.

Follow the same general procedures for this meeting as used for the previous two, including a written agenda. In terms of meeting format, utilize a combination of B and C "Problem Solving" and "Program Development." Start out the meeting by reviewing the program plan as it was originally developed including specifying people and

actions needed in order to implement the plan. In considering budgeting matters and implementing a program, you might utilize a "Problem Solving" approach in combination with the "Program Development" format. If the core planning group can foresee sufficient funds to initiate services, a key step would be to hire a coordinator. Upon initiation of the program, the core planning group may wish to consider becoming members of an advisory group or board and thereby continue to work on the program.

Each of the steps outlined above is enumerated below with lead-in comments and suggestions.

a. *Review of the program plan*

Begin the third meeting by soliciting comments, input, and suggestions concerning the program plan. Space is provided below for making notes. It may be useful to display the information on a blackboard or chart in order to keep the entire group involved and participating in the planning process.

NOTES: \_\_\_\_\_

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b. *Action plan*

Following the review of the program plan, the group should consider what steps need to be taken in order to implement the plan and who will be the best person to take each particular action. For example, if a letter of support is needed from each of the core planning group participants, this should be noted and a deadline for each person to turn in a letter should be given. Make sure that everyone understands what they are to do and when they are to do it.

ACTION PLAN		
Action Needed	Date to Complete	Person to Carry out

c. *Hiring a Coordinator*

When the program plan is in place and funding is assured, the hiring of a coordinator needs to be considered. The earlier the coordinator can be employed and involved in the planning and implementation of an in-home respite care program, the more smoothly the implementation of services might be expected to go. It is difficult for someone to implement a plan which he/she has not helped to formulate. Therefore, while you may not be ready by a third meeting to employ a coordinator, the sooner one can be designated, the better off the program will be. A great deal of the follow-through from planning which various members of the core planning group have done could be delegated to the coordinator. Hiring the coordinator during the early stages of program development also permits the coordinator to make suggestions and develop a feeling of ownership and commitment to the plan.

It may be necessary to continue the planning process without a coordinator if funds are not available to hire one. Furthermore, depending on the progress of your planning group and complexities in your community, a number of planning meetings in addition to the three designated here may be necessary before the group is ready to consider hiring. Considering this crucial step at this time would permit all members of the core planning group to begin to think about and to look for the right person.

As noted earlier, the coordinator is probably the key to providing quality in-home respite care. This person will be the primary individual in carrying out all aspects of the program. This individual's philosophy toward human services, and the ability to interact with professionals, families, and respite providers is paramount. To the extent that the person is well-organized, the program will be perceived as being efficient. Training skills, the ability to work with small groups, and the ability to articulate information in an effective manner are other necessary assets. To find one person who has all of these qualities can be difficult for the core planning group. Therefore, the sooner it can be considered and begun, the better off the in-home respite care program will be.

While the agency housing the in-home respite care program will have ultimate responsibility for recruiting and hiring the program coordinator, the core planning group can assist in this process. To provide some information and guidance in this process, Appendix G gives a sample job description along with some key points on personnel interviewing and legal issues related to equal employment opportunity. If the agency housing the IHRC program must retain control of the recruiting and hiring of a coordinator, the information in Appendix G and the following suggestions on recruitment of a coordinator might be of little interest to the Core Planning Group.

With the background information on job description and employment interviewing found in Appendix G, the group may wish to begin the search for a coordinator. If the Core Planning Group is to conduct or assist with the recruiting and hiring of the IHRC Program Coordinator, the following steps should prove helpful.

Set up personnel subcommittee composed of:

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Recruiting efforts (i.e., ad & newspaper contact, local employment office, distribution of job description):

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Applications received, and top candidates selected for interview on:

Date: \_\_\_\_\_ Time: \_\_\_\_\_ Place: \_\_\_\_\_ Name: \_\_\_\_\_

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Notes and comments on interviewees:

Name: \_\_\_\_\_ Date: \_\_\_\_\_

Comments: \_\_\_\_\_

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Name: \_\_\_\_\_ Date: \_\_\_\_\_

Comments: \_\_\_\_\_

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Name: \_\_\_\_\_ Date: \_\_\_\_\_

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Name: \_\_\_\_\_ Date: \_\_\_\_\_

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Name: \_\_\_\_\_ Date: \_\_\_\_\_

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Name: \_\_\_\_\_ Date: \_\_\_\_\_

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Comments: \_\_\_\_\_

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Name: \_\_\_\_\_ Date: \_\_\_\_\_

Comments: \_\_\_\_\_

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Name: \_\_\_\_\_ Date: \_\_\_\_\_

Comments: \_\_\_\_\_

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d. *Role of the Core Planning Group*

The continuing role of the core planning group needs to be considered. This consideration may precede point c, the hiring of a coordinator, or come any time after an agency has been designated to run the IHRC program. Contingent on policies and procedures of the agency designated to provide in-home respite care, the Core Planning Group would reorganize itself into an advisory group or policy-making board. In either case, the group would want to have a written statement regarding its roles, responsibilities, and authority. The group would also want to establish policy related to the election of officers and members of the group, including terms of office and tenure of members.

These matters should not be postponed with the assumption that they will take place, but rather they should be brought up specifically for consideration at a scheduled meeting.

Having been active in the preliminary planning, the group needs to remain active to see that decisions are implemented, issues dealt with, and effective, ongoing operations developed. The planning group can be extremely helpful to the new coordinator by providing background information on the development of the program including its ideologies and philosophies. Furthermore, the group can help the coordinator in recruiting potential consumers and respite providers. The group can also be facilitative in reviewing and contributing to the training program for care providers. A major function of the group on an ongoing basis should be program monitoring, setting or suggesting policies, and recommending changes in the program or procedures.

As an advisory group or board, the body will be less directly involved in the implementation or operation of the program. Their role should be that of setting policies and monitoring the program. Space is provided below for recording group decisions regarding the ongoing functions of the organization.

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### Summary & Follow Through

As stated previously, your program development may take a different course from that offered in this section. The important thing is not how you proceed with your program development, but that the program development meets your particular community needs. Outside consultants and funding sources may be helpful, but the plan development should belong to you and your community. Additional activities, meetings, or taking an entirely different direction from that outlined here is not the crucial element. As a core planning group, you may also need to exercise a great deal of patience in that things frequently do not move along as rapidly as one would like. Progress is sometimes a series of very small steps with the end result not being seen or reached for an extended period of time. Try to maintain motivation and involvement by having regular meetings which specify actions that each person can contribute to move the program planning and development along.

Having invested time and energy in the program planning process, the group will want to organize itself so that it can continue to contribute to the development of the program through the hiring of a coordinator. The group also has many useful roles to play in implementing the program and assisting the coordinator. Information in the two other units of this manual is designed specifically for a coordinator/trainer of the IHRC program. However, the group may wish to review these two units in order to adapt the ideas to their particular program and to be better informed when advising the program coordinator. At this point, you may wish to set up an additional meeting to follow through on the recommendations given above.

Next meeting place: \_\_\_\_\_

Date: \_\_\_\_\_ Time: \_\_\_\_\_



## APPENDIX A

### LEGAL SECTION

As the core committee plans an in-home respite care program for the community, some questions of a legal nature are sure to arise. Because the laws in each state vary widely, it is not possible to attempt in this manual to answer specific legal questions. Protection and Advocacy Agencies in each state have qualified legal professionals on their staff, and these people will be able to answer your specific questions or will be able to refer you to people who can help. Many communities have legal aid offices and these offices can be another resource for you. Another useful resource for legal problems is the Developmental Disabilities Law Project, 500 West Baltimore Street, Baltimore Maryland 21201.

The following is a list of questions that may be considered. This list was submitted to four (4) separate legal divisions including the Law School of Texas Tech University; Center on Developmental Disability Law, Kansas City University; Advocacy, Inc., Texas; and Hilgers, Watkins and Cazen, Attorneys at Law, Texas. Even though there was some variation on the response to the questions, the consensus of response is as follows:

#### *Question 1. What constitutes an employer-employee relationship?*

Response: The relationship between the employer/agency and the employee/provider will determine the liability, if any, of the employer. The label attached to any such employment arrangement will have no bearing. For an employer to be vicariously liable for the acts of his employee, there must exist a master-servant relationship (38 Tex. Jur. 2d-241). Such relationship is met if the employer controls what the employee is to do and how he is to perform the task (38 Tex. Jur. 2d-241). If the employee performs the work in his own manner, without any supervision from the employer, then the

employee is an independent contractor. An employer is not liable for the acts of an independent contractor (38 Tex. Jur. 2d-241). In a negligence action, if it is shown that the employee was performing services which are peculiar to the employer's affairs, then it will be presumed that a master-servant relationship exists. This means that the employer/agency would have to prove to the court that a master-servant relationship does not exist (38 Tex. Jur. 2d-241).

*Question 2. What is contract labor? If the agency supplies the provider with any type of "material," will this affect the definition of contract labor? If the employee/provider is paid only a volunteer stipend by the program coordinator, are the provider, "employee," and program liable? Is there a possibility that the liability/responsibility would be shared by the agency/program and the provider no matter how the employer-employee relationship is set up?*

Response: The law, as stated in response 1, will impose liability on the agency for the negligent acts of the provider, if the agency exerts any control whatsoever over the service provided. If the employment relationship is a volunteer arrangement or is labeled as "contract labor," it will probably have no bearing on liability unless the relationship is so attenuated that the employee is an *independent* contractor. The agency, however, will not be liable for the acts of the provider unless it is first determined that he acted unreasonably and thus injured another. Negligence is determined by a jury. Thus, if a provider performs some act which injures another, the agency will not be liable unless a jury determines first that the provider acted unreasonably. The court looks at all the facts and circumstances surrounding the event before it makes a decision.

*Question 3. If the employee/provider is paid by the parent, is the broker/agency program/program coordinator responsible for any accident? If the provider takes a client out in his/her car for an ice cream cone and has an auto accident, who can be held responsible/liable? Would the situation be viewed differently if the provider were taking the client to the hospital (an emergency situation opposed to an unnecessary trip) and has an accident?*

Response: If the provider is involved in an auto accident and the client is injured, the provider is responsible (and the agency is vicariously liable) to the extent he was at fault. If the provider was 40% negligent, then the provider must compensate for 40% of the client's injuries. The driver of the other car will be responsible for the remainder. It is very doubtful that such liability could be waived under any circumstances.

*Question 4. If the provider attempts to do something beyond his defined responsibilities (e.g. if the child has a piece of glass in his foot and the provider further damages the foot in attempt to get the glass out), is the agency/program/coordinator liable? Would it make a difference if the provider had training in the area of first aid?*

Response: Whether a jury would determine the provider negligent or not for removing glass from a child's foot is impossible to predict. Remember, the

court looks at all the facts and circumstances surrounding the event before it makes a decision. The best advice is to insure that the provider does the safest thing, i.e., contact the child's parents and obtain permission to take the child to the doctor. If the provider had specific training, for example, in rendering first aid, it would certainly be a strong indication that he did not act unreasonably, hence not negligent.

*Question 5. Consent forms / waivers are always discussed, and most program service units use various forms for a variety of incidents, (e.g., transportation release for the purpose of transporting clients to various activities; medical release form; emergency release form). Will the parent's signature on these forms hold up in litigation proceedings? If they are of benefit, what is the proper format to be used?*

Response: Use of waivers (consent forms) is good practice, even though these waivers are not binding in a court of law. Persons signing a waiver are usually more hesitant to pursue legal action. Just a simple statement that the provider has authority to admit the child for emergency care would suffice. The provider could consent to have a client treated for emergency care, if the emergency does in fact exist and no other options are readily available. The same simple statement of fact would suffice for transportation permission, giving the provider permission to transport the client.

*Question 6. Does the agency have a responsibility to check out a home to insure it is safe prior to its use for respite care? For example, if the parents have drugs within reach and the client takes them during respite care, is the agency and/or provider liable for negligence? Or, if there is a broken window in the home and the client hurts him/herself, is the agency and/or provider liable? Should these factors be noted before acceptance is made to care for the client?*

Response: If the premises are unsafe due to acts or neglects on the part of the parents, and the child is injured because of such, the parents are responsible, not the provider. But, it could very well be the case that the provider is also at fault to some degree, especially if the dangerous condition is open and obvious to the provider. It could well be the case that the provider would be partially negligent as would be the parent.

*Question 7. If the provider, on his/her own, makes arrangements to care for a client after being sent by the agency (if the provider makes arrangements to provide respite care on his own the next time), is the agency liable for having made the initial placement / match up?*

Response: Relevant to the whole area of vicarious liability on the part of the employer / agency is the scope of employment. If the provider injures a client when the provider is not in fact on duty, the agency is not liable. Thus, if the provider makes arrangements on his own to care for the child, then he is acting outside his scope of employment, and he alone is responsible, not the agency. Moreover, if the provider, while on duty, performs some act which the agency expressly forbids or is obviously outside the scope of employment, then the agency again is not responsible.

*Question 8. If the provider is injured by the client or is injured in an accident in the family's home, who can be held liable? Parent? Client? The agency/program? Program coordinator?*

Response: If a provider is injured by the handicapped person, the handicapped person, under Texas law, is liable for his tortuous acts. This is the general rule in Texas, and may well vary from state to state. If the handicapped child is not liable, it would most likely be his parent or guardian who is liable. It is very unlikely that the agency would be liable under any circumstances.

This last question is answered by a communique from the Department of Labor, and the response was made to the National Association of State Mental Retardation Program Directors, Inc. The NASMRPD, Inc., requested the formal review regarding group home staff and relief staff. Respite care providers, in most of the programs reviewed, are considered part-time staff. Therefore, if you contact your local Department of Labor to discuss the issue, determine prior to the contact whether care providers of the program are full or part-time staff.

*Question 9. In providing respite care for an extended period of time, is the agency required to pay the care provider for each complete 24 hours of service, including sleep time?*

Response: Henry T. White, Jr., the Deputy Administrator of the Labor Department's Wage and Hour Division, points out that sleeptime, under the Department's existing policies, is generally compensable unless it falls within two specified exceptions—either the employee is "on duty for 24 hours or more" (in which case up to eight hours of sleeptime may be deducted in calculating the employee's wages) or "the employee resides on his employer's premise on a permanent basis or for extended periods of time" (in which case any "reasonable agreement" between the parties concerning the amount of hours worked will be accepted if it takes all of the pertinent facts into consideration). Additionally, the legal groups indicated a possible assistance would be to obtain or negotiate a contract with the care provider to work a specified period of time for a specified amount of money. One must be careful to avoid a specified number of hours for a specified amount of money *per* hour; this would make it necessary to pay the provider for sleep time.

It is important if you have legal questions to consult an attorney, school of law, or an advocacy group that is legal in nature to know what the exact legal implications for your community/state may be.

## APPENDIX B

# PROGRAM PLANNING AND EVALUATION

### Introduction

Most of the information and suggestions given in this Appendix are from a training package developed by the Research and Training Center in Mental Retardation at Texas Tech University entitled *Program Planning and Evaluation in Community Based Agencies: Instructor-Free Training for Participatory Management Teams*. In addition to the information synthesized here, the training package has ten sessions entitled: "Generalizing Competencies Through Instructor-Free Training, An Ideology for Human Services, A Survey of Management Theory and Style, A Conceptual Model for Program Planning and Evaluation, Guidelines for Effective Decision Making and Strategy Implementation, Budgeting, Evaluation: An Integral Part of Program Planning, Funding and Grantsmanship, Synthesizing and Using Your Training, and A Model for Community Planning." Realizing that progress in developing a proactive, comprehensive program planning and evaluation approach has been slowed by the fact that many planners, administrators, and management personnel in human service facilities were trained as clinicians as opposed to administrators, the Research and Training Center developed this instructor-free training package, and you are referred to these materials for additional information and potential use as an in-service training instrument.

Because planning is something we frequently do, almost unconsciously, its basic tenets seem simple and self evident. But the type of planning we most often employ is spontaneous and usually quite nebulous. In the rush of decision making, critical considerations are often overlooked or purposely by-passed "in the interest of time." This type of planning, at best, will meet only immediate problems and does nothing to bring about desired outcomes. It will only solve the crisis at hand. Perhaps you feel you have no time for anything other than spontaneous decision making. Yet, the

busier you are, and the more limited your time, the more you can benefit from a planning system geared to reach clearly defined outcomes through specified means. Gallagher, Surrles, and Hayes (1973) identified three major advantages of such a system.

**Providing a Guideline.** Well-stated plans are an asset to project staff. Knowing the purpose and direction of a project reduces anxiety and facilitates decision making.

**Supplying Information.** Well-stated plans help prevent confusion by communicating project intentions to those not directly involved. The funding agency, those interested in replicating the project, and the clients who might participate are among those who would find a planning statement helpful.

**Forming a Basis for Evaluation.** Evaluation is necessary in order to determine a project's effectiveness; program planning provides the core for this evaluation process. Quite simply, if you can clearly define where you are going, it is much easier to tell if you have arrived.

To begin developing a program plan, you will need to have some conceptual framework within which to work, and which has the essential elements of:

Goals which highlight intentions and give general directions.

Objectives which specify the steps toward reaching a goal.

Strategies which tell how the objectives will be implemented.

Evaluation which determines whether the strategies are being implemented and whether the objectives are being met.

Each of these essential elements to a program planning and evaluation system will be dealt with separately, along with specific examples for an IHRC program. It should be noted that as you develop your program planning and evaluation system, significant others should be involved in the process, such as the IHRC Program Coordinator and agency director (if available), members of the core planning or advisory committee, and others who may be in a position to influence the operation of the program.

## **Goals**

Goals or goal statements serve primarily to highlight intentions. They tell, in a very general way, what will happen to a target population as a result of services delivered or other activities taken. Because goals are intended only to give the broad direction of an agency or program, they usually are abstract and often based on value judgments. Although in most cases the executive director and the board of directors develop agency goals, suggestions from advisory groups, consumers, or middle management are welcome, if not solicited. In addition to enlarging the perspective of policy makers who are frequently isolated from day-to-day concerns of the agency, this process gives advisory groups or program coordinators a vested interest in seeing programs succeed and promotes their future cooperation. But even if you

# PROJECT WORK PLAN EXAMPLE

Goal Statement I: To develop and implement an effective in-home respite care project

OBJECTIVE	STRATEGIES	EVALUATION
1. An in-home respite care Project Coordinator will be hired by August, 1982	<ul style="list-style-type: none"> <li>• Posting of job opening and job description with the Personnel Department of agencies</li> <li>• Notification of job opening to local personnel sources</li> <li>• Notification of job opening to the State Employment office</li> <li>• Place ad in local papers</li> </ul>	Project Coordinator hired
2. Project Coordinator will be oriented to the agency's general service programs and procedures during the first two weeks of employment.	<ul style="list-style-type: none"> <li>• Review of all agency policies and procedures</li> <li>• Introduction to other programs at the agency</li> <li>• Review of pertinent laws and regulations for service provision</li> <li>• Review of the agency's service program coordination and management procedures</li> <li>• Review of client program plan procedures and operation of the interdisciplinary team</li> </ul>	Documentation of all steps will be dated and placed into the Project Coordinator's personnel file.



have no voice in developing the overall goals of your agency, you should at least be aware of them in order to ensure that achievement of your IHRC program goals will bring the agency closer to fulfilling its mission.

In stating goals, you should strive to be positive while remaining realistic, and even though they should be stated in broad terms, they must be understandable to everyone who will be involved in working toward them. While you may have many goal statements, you will probably begin working on only three or four. To help you choose the goals you would like to begin work on, put the list you have developed in priority order. You might consider factors such as how soon the goals should be met, what the consequences would be if not met (or not met soon), and how many people they affect. Another important consideration in determining priority order is whether or not the goal can logically be obtained before other goals on the list are accomplished. For example, deciding on an agency to house the IHRC program would need to be done before applying for funds. Developing good working relationships with other service provider agencies in your community may be a prerequisite for providing your client/consumer family with effective referral information for additional services. The major IHRC program variables discussed on pages 1.13-1.16 should give some direction to the core planning group regarding goals they should consider. The chart found at the beginning of Unit II (p. 2.6) will be helpful in goal development and priority setting when the coordinator begins to implement an IHRC program.

Some examples of goal statements related to information provided earlier in this unit would be:

1. Select the best agency for affiliation with the IHRC program.
2. Develop program budget.
3. Obtain financial support for program.
4. Hire a program coordinator.

### **Objectives**

Objectives must be written in clear, precise language that indicates both measurable achievements and time limits for reaching them. They are the more crucial part of the program plan, for if they are stated well, they make it possible to ascertain, through various evaluation procedures, whether progress is being made toward reaching goals. A well-written objective must be behavioral, outcome-oriented, and time linked. That is, it must describe a behavior that is observable and measurable, it must include a means of determining when the behavior is complete, and it must specify how long it will take.

One goal might be, "Select the best agency with which the IHRC program may become affiliated." To reach this goal, a planner might resolve to find out more about the need for respite services. While the intent is commendable, this plan of action is not nearly specific enough to be effective. To translate the idea into an objective, you first need to state it in behavioral terms. The IHRC core planning group must define



"Find out more about needs." Does this mean that they will ask about IHRC services the next time they spot a member of a consumer family on the street? Does it mean that they will include clients/consumer families in their next social gathering so they can discuss IHRC? Obviously, it is difficult to measure or observe "Find out more." However, when the objective is to "Conduct a needs survey of parent/consumers and service agency professionals on IHRC services," it will be easy to tell when that has taken place. In some cases, it may be necessary to be even more specific about who will be involved in the activity. In this example, the objective should specify who will develop the needs questionnaire and to whom they will be sent. That is, will the questionnaire be given to the local ARC, UCP, Coalition of the Handicapped, or some other consumer organization?

For an objective to be *outcome-oriented*, it must include a means of determining when the behavior is complete. That is, what criterion must be met in order for it to be considered a success? In this case, the objective might specify when the questionnaire will be ready for mailing, and what information will be solicited from whom.

The final requirement—to make the objective *time-linked*—can be accomplished by specifying that the questionnaire tabulation will take place within a certain period of time. It is also helpful to specify the duration of the activity.

The entire objective—as a behavioral, outcome-oriented, time-linked statement—should read, "Need for an IHRC program will be documented by tabulation of results from questionnaires mailed to all identifiable families who have members that are handicapped and to professionals in local human service agencies within the next two months."

Just as it is possible to write many goals for one program, it is also possible to write a multitude of objectives for one goal. And while some goals may necessitate developing objectives with just the core planning group, others may require objectives from several diverse groups, agencies or persons, (e.g. personnel, accounting, and business offices of the mother agency may be involved with recruiting and hiring the program coordinator). To keep your program plan from becoming too unwieldy and confusing, you will find it helpful to sequence these objectives and put them in priority order, just as you did your goals. Once again, you may find it more profitable to concentrate resources on three or four objectives at first. If time permits, you may work on additional objectives as your top priority objectives are achieved.

### Strategies

Just as objectives are more specific than goals, so are strategies, the third element of the program plan, more specific than objectives. Objectives outline the steps necessary to reach the goal, while strategies outline the procedures necessary to reach the objectives. And just as there may be several objectives for one goal, there are usually several strategies for each objective.

Strategy statements describe what will actually be done in a project. To be effective, they must specify *who* will implement the strategy, *what* procedures or techniques will be used, *how* they will be implemented and *when* and *where* they will be carried out.

Following through on the previous example, it is now necessary to develop strategies for insuring that the items on the questionnaire solicit information that will help in planning an IHRC program. Local consumer groups will need to be contacted to develop a mailing list. Since your objective stated that the tabulation must take place within the next two months, you should specify that the initial contact of consumer groups take place over the telephone (where) within the next two days (when). A second strategy, based on the outcome of the first, might involve obtaining a roster of their members. As mentioned earlier in this section, even though several persons might be involved in developing the strategies, it is important to designate one person who will be responsible for seeing that they are carried out (e.g., who will get the list).

Even though the strategies in the example appear workable, there may still be barriers to achieving the objectives that have not yet been considered. For example, there may be a cost factor in duplicating and mailing the questionnaire. Obviously, some means of overcoming such a barrier must be incorporated into your strategies.

### Evaluation

Evaluation is an integral part of any program planning system. In addition to being a mechanism for responding to external demands for information from funding sources and advisory groups, evaluation is a means of determining whether the program objectives, and thus the goals, are being achieved. Data gathered during evaluation can be translated into useful information which you will find helpful in day-to-day decision making. Thus, evaluation is a continuous process which is built into the program plan and carried out as a legitimate function.

Although the evaluation information required will vary based on decision makers' needs and purposes, evaluation generally falls into one of two categories, both of which are necessary in an effective monitoring system. *Process evaluation* focuses on whether *strategies* are being carried out. It is an ongoing process which requires monitoring project objectives on a daily basis. A summary of this information can then be used as a basis for the *product evaluation* which determines whether or not the strategies are helping achieve the project *objectives*. The product evaluation is often a summary of process evaluations taken over a period of time; it usually indicates what a target population was like when a project began and what the population was like after the project was completed. In the example cited earlier for instance, the process evaluation would involve determining whether you were able to set up a mailing list and develop a questionnaire and receive back a reasonable number of complete forms. The product evaluation would show the tabulated results of the needs assessment questionnaires.

By examining a well-constructed product evaluation, it is possible to tell with certainty whether or not a particular objective has been reached. If it has, you are ready to move on to the next objective. If it has not, the next step is to examine the process evaluation related to that objective; that is, examine data concerning the various strategies you have employed in order to reach the objective.

If the strategies and their evaluation are both specific and clear cut, it is possible to determine exactly what does not work. In the previous example, if you implemented

all of your strategies but still did not receive any completed forms back, then perhaps you would want to follow up with a letter or phone call. It is important to remember that there is no shame in having a strategy that does not work. However, continuing to use strategies that do not work is wasteful, and only by examining results can one make needed and necessary modifications.

In summary, evaluation:

- flows easily if clear and reasonable goals, objectives, and strategies are formulated;

- not only helps monitor what is happening, but suggests alternatives and gives direction to strategy revision;

- should consist of both product (objective) and process (strategy) components.

### Summary

Program planning and evaluation are means of effectively and efficiently coordinating a variety of program activities in order to reach a specified outcome. This system generally is aimed at producing changes in a group of people and is most effective when utilized by a participatory management team. It requires that the team develop four integrally-related plan components—goals, objectives, strategies, and evaluation.

- Goals* state the general direction of a plan or project.

- Objectives* specify behavioral, outcome-oriented, time-linked steps toward reaching a goal.

- Strategies* outline steps toward reaching an objective; they tell what procedures will be used, how they will be implemented, who will carry them out, and where and when they will take place.

- Evaluation* determines whether the strategies are carried out and the objectives are met.

Operating according to well-thought-out written plans helps reduce staff anxiety and facilitates decision making by providing purpose and direction. Effective program planning also provides a basis for evaluation, which generally is conducted in two stages. *Process evaluation* is an ongoing monitoring of day-to-day activities (strategies) in a project. *Product evaluation*, usually a summary of the process evaluations, is a means of determining whether or not project objectives are being met. These evaluation procedures should remain flexible enough to meet both internal and external requirements for project information.

## APPENDIX C

### RESOURCES FOR GRANT WRITERS

#### A. Government Grants

Morris Associates, Inc., Governmental Affairs Consultants, Dupont Circle Building, 1346 Connecticut Avenue, NW, Washington, D C 20036. (202) 797-0647

*Morris Report on Federal Health Policy.* \$140 per year.  
Published semi-monthly.

National Association of State Mental Health Program Directors, 1001 Third Street, SW, Suite #114, Washington, D C 20024 (202) 624-5837.

*Federal Funding News.* \$30 per year. Published periodically.  
Provides updated information on legislation and regulations affecting mental health.

Adapted by G. F. England from Vernon Betourne and Gerard J. O'Brien, *Grantsmanship and Proposal Preparation Workshop*. Texas Department of Mental Health and Mental Retardation (Ed.), Austin, TX, 1977 and previously used in *Program Planning and Evaluation*, Texas Tech University, Research & Training Center in Mental Retardation, 1977.

U. S. Government Printing Office, Washington, D C 20402 (202) 275-2051

*Catalog of Federal Domestic Assistance.* \$22 per year.  
An essential reference source. Most authoritative compendium of federal grant program information. Provides program descriptions, eligibilities, deadlines, funding levels, and contact names and phone numbers. Updated annually.

*Commerce Business Daily.* On a 6 month trial basis, price is \$80 per year, first class; \$60 per year third class; normally \$150.00 per year first class; \$100.00 per year third class. (202) 783-3239.

Daily list of government procurement invitations, contract awards, and sub-contracting leads.

*Federal Register.* \$75-\$300 per year. Published Monday through Friday. Lists all proposed federal regulations. Provides guidelines governing grant policies, objectives, eligibilities, and descriptions of new legislation.

*Grants Policy Statement.* \$1.75 per copy. Stock number 017-020-00058-7. A must if applying for a federal grant. Contains lists and guidelines for all areas of grant administration.

#### B. Private Foundation Grants

The Foundation Center, 888 Seventh Avenue, New York, N.Y. 10106. (212) 975-1120.

*Foundation Director.* 136 South Broadway, Irvington, N.Y. 15033. \$45. Listing of foundations by state. Accounts for 80% of foundation funding.

*Foundation News.* 1828 L Street, NW, Washington, D C 20036 (202) 466-6512. \$24 per year.

Contains feature articles on current events and trends in the foundation world. Also includes a grant index which indicates recent awards by foundation and by state.

Regional Depository Library, The Hogg Foundation for Mental Health, University of Texas, Austin, TX 78712.

#### C. Government and Private Foundation Grants

The Grantsmanship Center, 1031 S. Grand, Los Angeles, CA. 90015. (213) 749-4721.

*The Grantsmanship News.* \$28 per year.

Timely, accurate, informative feature articles about grants and grant writing. Analysis of public and private grant programs as well as notices of new grants available.

Marquis Who's Who, Inc., 200 East Ohio Street, Chicago, IL 60611.

*Grantsmanship: Money and How to Get it.* \$7.50.

Excellent discussion of the art of grantsmanship. Covers foundation and government grant writing. Includes samples and references to other needed literature. Brief and relevant.

D. General Reference

Internal Revenue Service Offices

*How to Apply for Recognition of Exemption for an Organization.*

Publication number 557. Free.

Provides details of applying for tax exempt status for nonprofit agencies. Exemption is necessary for applying to all foundations.

U. S. Government Printing Office, Washington, DC 20402. (202) 275-2051

*Grants Administration Manual.* \$32 per year.

Helpful if you've already received a federal grant. Full details of federal grant administration requirements.

*Guide for Establishing Indirect Cost Rates, Guide for Colleges and Universities* (OASC-3), \$2.00

*A Guide for Nonprofit Institutions* (OASC-5, Rev.), \$4.25

*Guide for State Government Agencies* (OASC-6). \$4 each.

Pamphlets that provide principles and standards for determining allowable costs of a project before applying for a government grant.

*Government Organization Manual.* \$11.00 per year.

Official federal government handbook which describes the purposes of government agencies and lists top personnel. Also lists committees, commissions, etc.

## APPENDIX D

### OUTLINE FOR EFFECTIVE MEETINGS

The following is a structured outline which we offer as a suggestion to aid you in conducting effective meetings. You may wish to modify portions of the outline to meet your particular needs; however, the outline should first be learned and then shared with those people you frequently interact with in meetings. By sharing this outline, you share the expectancies for the structure and outcome of the meeting with those participating. The important thing is to learn it well so that it can be used comfortably.

#### I. AGENDA FORMAT

##### AGENDA

Date: \_\_\_\_\_ Time to Convene: \_\_\_\_\_

Place: \_\_\_\_\_ Time to Adjourn: \_\_\_\_\_

TO:	List participants
FROM:	Person calling the meeting or the chairperson
TOPIC:	Items to be covered at the meeting (List the items to be covered, any brief details necessary, and estimated time to spend on each)
ENCLOSURES:	Include handout materials pertinent to the meeting topic and include texts, forms, etc., to be reviewed or studied.

**INSTRUCTIONS:** Specific instructions that participants must complete before attending the meeting include:

1. What they are to do.
2. What they are to bring.
3. Solicit additional information.

## **II. ESSENTIALS OF EFFECTIVE MEETINGS**

- Convene on time
- Good opening/introductions
- Well-planned agenda (in order of priority)
- Clear roles (leader, recorder, participants)
- Appropriate environment (comfortable temperature, well lighted)
- Materials/equipment
- Free from interruptions
- Definite adjournment time

## **III. PRE-MEETING CHECKLIST**

- Precise purpose—objective
- Written announcement (time, purpose, location, etc.)
- Tentative agenda distributed with vital back-up materials
- Predetermined adjournment time
- Identify audience
- Identify materials needed (visuals, equipment)
- Who can help? Advise in advance
- Plan ingredients—all points to be made
- Estimate time for each agenda item
- Plan opening
- Integrate impact features
- Examine texture (variety)
- Dry run visuals/equipment

## **IV. ROLE OF CHAIRPERSON**

- Begin on time
- Provide overview
- Keep on target
- One agenda item at a time
- Cut off redundant debate
- Be sure one person does not dominate
- Draw out the "timid/perplexed"
- Encourage full discussion
- Keep climate relaxed/wholesome
- Use rules for brainstorming



- Use rules of order
- Tap resources of audience

#### V. ROLE OF MEETING PARTICIPANT

- Do advance preparation
- Be on time
- Raise questions for clarification
- Demonstrate responsible good manners (attitude/behavior)
- Accept share of work—offer to help
- Stick to the point
- Help others to stay on topic
- Be sensitive to others' feelings (particularly chairperson)
- LISTEN ACTIVELY—LISTENING WITH WARMTH IS CONTAGIOUS

#### VI. POST-MEETING CHECKLIST

- Minutes or record distributed—24 hours
- Clear follow-up assignments and timeline
- Evaluation
- Next meeting (date/time)
- Location
- Tentative Agenda
- Responsibilities

#### VII. MEETING RECORDS

- Purpose—to provide:
  1. minutes of meeting to participants
  2. concise, right-to-the-point notes
  3. opportunity for recorder to be active participant
  4. basis for summarizing the meeting
  5. critical elements and decisions made
  6. immediate dissemination
- Objective—to provide:
  1. date, time convened and time adjourned
  2. name of recorder
  3. names of participants
  4. specific topics covered
  5. time spent on each topic
  6. decisions reached and actions to be taken
  7. responsibilities for followup
  8. deadlines for action to be taken
  9. list of handouts distributed at the meeting

Meetings generally follow three sequential phases.

*Phase I:* Setting objective(s) and commitment to objective (s).

*Phase II:* Generating and selecting alternatives.

*Phase III:* Deciding on specific commitments and criteria of success.

*Phase I:* **Setting objective(s) and commitment to objective(s)**

Step 1. Specifying objectives

The purpose of Step 1 is to make sure that people in the meeting agree on the objectives. This sharing is a kind of contract setting. It establishes an atmosphere of "let's get down to business." This should be accomplished during the first few opening comments and can be greatly facilitated by preparing a written agenda. Also during these opening comments, there should be an agreement reached on the process. Will the decision-making process be by consensus or consultation?

Step 2. Reviewing data related to objectives

Parties must have or develop the same perception of what is presently happening in the situation being discussed. They must limit or discipline themselves to the objectives of the meeting. Sharing information related to in-home respite care prior to the meeting can help set this objective.

Step 3. Selecting a focus

A focus on one or two issues within the objectives selected above allows for more specific planning and more rapid progress. It also helps keep the conference short. *A short conference is usually more productive than a long one.* For this first meeting of the core planning group for home respite care, there are limited and specific objectives which you might wish to keep in mind, and they are outlined for you in the next section dealing with the first meeting.

Step 4. Agreeing on the necessity of a change (decision)

The purpose of this step is to seek a commitment to change. This step should be short and done only once. Are the people at the meeting willing to commit themselves to the development of an in-home respite care program?

*Phase II.* **Generating and selecting alternatives**

Step 5. Proposing alternatives

More than one alternative should be considered before a choice is made. Develop an atmosphere which allows people to express ideas openly. For example, what agency would be most appropriate to house a home respite care program?

#### Step 6. Selecting an alternative

It is difficult to implement several changes at once. If one alternative is selected, the chances for success are better than when more than one alternative is selected. For example, if there is a first, second, and third preference for agencies to house the in-home respite care program, begin working on the first preference only. If it does not succeed, move to the next alternative.

#### Step 7. Planning specifically

Specific planning includes the development of goals, objectives, strategies and evaluation processes. It is suggested that a specific plan be written so that all parties will have a record of their commitments. A record makes the participants more accountable and the process more clear.

### *Phase III:* **Deciding on specific commitments and criteria for success**

#### Step 8. Establishing criteria

Establishing times, dates, etc., sets a realistic expectation for the accomplishment of agreed-upon decisions. This is particularly true of target dates. For example, who will contact whom within the agency of preference, by when, regarding the housing of an in-home respite care program?

#### Step 9. Giving feedback on the meeting

This step is the sharing of opinions on the meeting process. It allows the group to stop, reflect and comment on the perceptions of the person(s) with whom you are dealing. You should learn how to ask this question to receive an open and honest answer. The group should feel comfortable giving feedback to both members and group leader. This is not a time for reacting defensively and downgrading perspectives. It is a time for listening and trying to understand the perspective(s) offered.

#### Step 10. Reviewing commitments

This final checking out and restatement of commitments is necessary. It is a deliberate redundancy which will prevent any major misunderstandings. If a person verbalizes a commitment, there is greater chance that the person will fulfill the commitment. After the restatement of commitments, the meeting should end.

## APPENDIX E

### RESPIRE CARE NEEDS ASSESSMENT SURVEY

#### Goals (for parent survey):

1. Assess the present need in your community for respite services.
2. Determine an estimate of how frequently relatives would utilize respite care services.
3. Determine the importance of respite care services for the families of the handicapped.
4. Ensure that the services you intend to provide are not already available in your area.

#### Items to Include in Survey:

1. Definition of respite care and particular type of respite care that might become available (e.g. in-home, care provider's home, etc.).
2. If available, would you (the parent) use respite care?
3. If yes, how often and for how long (e.g., evening, overnight)?
4. How much would you be willing to pay?
5. On a scale of 1 (no need) to 7 (great need), rate your (parent) need for respite care.
6. How long has it been since you have gotten out to a social event with your spouse and/or family without your family member who has a handicap?
7. What arrangements do you usually make (if any) to care for your family member when you are out? Is the care giver specially trained? How much do you pay?

8. What provisions do you have available for emergency situations when you are unable to care for your relative?

### **Guide to Needs Assessment Surveys**

The purpose for conducting a needs assessment survey of parents of handicapped people and professionals in your area goes beyond the basic reason of determining need. The results of your survey may be one of your strongest aids in your efforts to obtain funding and support. It is one thing to say that "I have observed a need in our community for respite care," but it is another to have data to show that this type of service is not available anywhere else, that it will be used by families and may even save money for taxpayers.

A program that includes in its proposal a rationale, including statistics pertaining to need has a distinct advantage over other proposals. It may also help you get the support of local agencies if you can say "X% of your clients need this service."

In preparing for your needs assessment surveys, try to determine to whom you need to plead your case. With that in mind, you may wish to tailor your questions in such a way that particular areas are addressed to permit positive responses that may be used to assist you in providing data to a given source. Try to predict the type of information that would be important not only to help you plan a program, but also to provide needed evidence to support potential grant proposals.

### **Respite Care Needs Assessment Survey (Parent)**

The following are tips in the design of questionnaires:

1. Try to keep the questionnaire as short as possible without sacrificing valuable information.
2. Short answer questions (e.g., checklist, multiple choice, yes-no, short fill-in-the-blank questions) are more likely to be answered and are much easier to tally than essay questions.
3. Be clear in your wording. Avoid use of technical language as much as possible.
4. Design your survey with your specific needs in mind. Before you write the questions, determine what type of information is needed to assess your community's situation.
5. Since return rates in mailed-out questionnaires are rarely greater than 50%, it may be necessary to "track down" overdue questionnaires.
6. If you plan to distribute questionnaires in person (e.g., at a local meeting of ARC), ask the people to fill out the forms that night and give them back to you before they leave. Bring pencils.
7. People will generally be in favor of any new program for handicapped individuals, even if they have no intention of using it. So beware of apparent overwhelming enthusiasm or support.

8. Be careful not to bias your survey sample by making premature promises about your program. Remember at this point you are only assessing community needs.
9. Leave space at the end of each question or at the bottom of the questionnaire for comments. Sometimes this becomes your best source of information.
10. If you promise anonymity, be sure to keep your promise.
11. Make sure people responding to your survey know where to return the forms and to whom to address questions for additional information.
12. Remember you are trying to elicit help from these people, so be courteous. At some future date, you may seek to recruit them as consumers for your service, so this is your chance to make a positive impression.
13. Be neat in your layout of the questionnaire. Check for typos and other errors. Avoid using shiny copy paper, since it is often difficult to write upon.
14. If you are distributing the surveys in person, be sure to dress neatly, behave responsibly, be on time, etc. Remember you are a representative of the service, and if you do not look responsible, the service may look irresponsible.

#### **Respite Care Needs Assessment Survey (Local agencies, professionals, etc.)**

##### **Goals:**

1. Assess the present need in your community for respite care services.
2. Locate programs in your area that may already be providing similar services. If you find some, you may wish to have this program serve as a supplement to fill in the gaps in the existing program by providing services to a different population.

##### **Items to Include in Survey:**

1. Definition of respite services.
2. Are you aware of any such services in your area?
3. If yes, who is served? What restrictions are set in client selection? Name and phone number of contact person.
4. Would you or your agency be willing to:
  - a. Provide space for housing a respite care office?
  - b. Provide staff (e.g., clerical, professional, message service)?
  - c. Distribute materials to consumers or potential care providers?
  - d. Assist in the training of new care providers? If so, in what capacity? For what topics could you provide instruction?

- e. Assist in the recruitment of providers and consumers?
  - f. Release your mailing list to use for needs assessment purposes? For recruitment of consumers?
  - g. Assist in the funding of this program?
  - h. Serve on steering committees, an administrative board, etc.?
5. Rate the need for respite care services in your community on a scale of 1 (no need) to 7 (great need).

## APPENDIX F

### PROGRAM COSTS AND BUDGETING

While money and operating costs of a program are a reality, frequently they can interfere in planning. Those involved in community planning are often tempted to rush out and seek funds, as well as tailor their program to meet the funding requirements of a particular source. Unfortunately, local needs and services too often do not match the outsider's program design.

Through the community planning process, identification of needs as well as resources can be made, and a plan outlining goals, objectives, strategies, costs, and evaluation procedures can be developed. If local, ongoing, currently-existing funds can be allocated to the implementation of an IHRC program, this would be preferable. If, after careful analysis, it is the consensus of the planning group that outside funds must be sought, then an application to potential funding sources still needs to be developed.

Regardless of whether funds are allocated from existing ongoing sources or from outside sources, you will need to develop a budget and have a reasonably tight fix on program costs. To assist in this process, the following information and guidelines are given based on data from a variety of programs throughout the United States.

#### **IHRC Cost Variables**

A number of variables must first be considered when developing in-home respite care services, costs and budgets. For example, some programs operate from almost a total voluntary basis. The administration, coordination, training and provision of in-home respite care is done by volunteers, with the only payment being a fee to the respite care provider being paid by parents/ family. Other programs are totally professionally staffed from administrator to coordinator, trainer and respite provider and totally subsidized with no fees being paid by the parents/ family. Within these two extremes,



most programs are professionally staffed with a coordinator, utilize volunteer trainers and subsidize for home respite providers based on a sliding scale related to the parent/family income. For purposes of discussion here, we will use the latter type of program as an example. For consideration and discussion, we will present a typical budget followed by a discussion of the budget and fees with a table of data from various programs. This section on cost and budgeting will conclude with a discussion on financial control and limitations on services and a series of questions on budget to be considered by your core planning group.

### **Budget Justification**

The Project Director will provide general administrative, supervision duties and act as liaison between the in-home respite care program and the agency. A full-time coordinator and a half-time secretary are required in order to maintain records, coordinate activities, interview, match and provide in-home respite care services.

Consultant services are required in the training of the home respite care providers. It is estimated that three training programs will be conducted during this budget period with three consultants used at each program with an average cost of \$125 each. Subsidy for families in economic need is budgeted at \$8,000 and will be based on a sliding scale of family income.

Local travel and subsistence are necessary in visiting and interviewing consumer families and potential providers. Out-of-town travel for the coordinator to visit other programs and to attend at least one professional meeting is also budgeted.

Equipment will be needed for two offices, including one typewriter.

Supplies necessary to operate the offices and record information will be required. Some training supplies will also be necessary for providing potential providers with training.

Other expenses related to the operation of the program include postage, telephone, administrative overhead, rent, and utilities budgeted at \$5,000.

The total budget cost of \$43,600 would be equivalent to keeping only a few people in a state residential program for a year. By providing this needed in-home respite care service, many families may be able to maintain their severely handicapped family member at home.

### **Fees for In-Home Respite Care Service**

In virtually all of the programs which we have contacted, some type of fee is paid by the parent/family who receives in-home respite services. These fees are typically paid on some type of sliding scale basis related to the parent/family income. In determining fees to be charged, several important factors should be taken into account. These factors include the funding base of the program, economic climate of your area, overhead and administrative cost, travel involved in the service area to be covered, and other sliding scales set up by your agency or similar programs in your community.

In nearly all of the agencies we have had contact with, there were some funds available to assist families of low income. Many of these formulas were difficult to decipher, but most were based upon the yearly income of the family as reported on their last Income Tax 1040 Form. As the families' income increased, the fees for respite care services generally increased. Most agencies had a maximum rate that families could be charged. When the family's income was on the lower end of the sliding scale, the respite provider would be paid through subsidies from the respite care program. In no case did we find any program unwilling to provide respite services on the basis of an inability to pay.

Other factors influencing the fee schedule were the number of dependents living in the home. Families with large numbers of children were sometimes given lower rates for respite. When the provider is required to care for additional children beyond the handicapped person, the rates are adjusted to reimburse the provider for this additional responsibility. For example, if the provider is caring for a handicapped person and a non-handicapped sibling, an additional fifty cents per hour might be paid.

While not generally observed, other factors which might affect the fee rate could be the severity of disability, experience and/or previous training of the provider, and tenure in the in-home respite care program. Again, while these factors were not generally considered, your program might decide to implement such a fee schedule to encourage and/or retain better qualified respite care providers.

In nearly every case we have observed, the agency establishes some type of hourly rate as well as a daily rate for service. Daily rates are usually not computed on a twenty-four hour basis. Daily rates take into account the fact that the provider will be spending approximately eight hours sleeping and that the handicapped person may spend a substantial amount of time out of the home—at work, in school, or other day programs. In such cases, the daily rate would be proportionately less than the actual twenty-four hours. Weekly and monthly rates may also be established if your agency plans to provide longer terms of respite care. For questions related to legal aspects of wage and hour regulations, you are referred to Appendix A.

Some of the agencies with whom we have had contact also charge the consumer family a one-time registration fee (\$5-\$10). This fee is used to cover some of the basic administrative expenses associated with processing a new consumer and, in some cases, is used as a source of funding to subsidize lower income families.

There are a number of different ways agencies approach the payment to the in-home respite care provider. These different approaches appear to be related to legal issues in regard to the employer/employee relationship and liability (see Appendix A). Some of these relationships involve the following:

1. Utilizing a broker to act as liaison between the family and provider.
2. Utilizing a contractor to contract with respite providers in performing certain services.
3. Utilizing a normal employer/employee, temporary, part-time relationship.

Frequently these employer / employee relationships also affected fees; some merely suggested a fee schedule for the family to pay to the respite provider. At other times, the family paid part of the fee to the respite provider, and the agency paid a subsidy. In other cases, the family / consumer would pay the respite program and the respite program would issue a paycheck to the provider. Regardless of which approach you utilize, you should review the legal implications as presented in Appendix A.

### **Budgetary Controls**

Most agencies have established some budgetary controls for their programs related to length and frequency of use and amount of subsidy provided to a given family. These limitations are difficult to formalize with a new program and are usually dictated by supply and demand. If there are many more families requesting services than there are available providers, your program may have to impose some limitation on how frequently one family may use the service. By placing a total amount of subsidy money available to any given family, budgetary control can be maintained.

To maintain program and monetary control, the length of stay in the respite program may be limited. For an example, in-home respite care services will be provided for no longer than two weeks. Frequently respite providers cannot stay for protracted periods of time, and a combination of different providers may be utilized for a protracted period of respite. This combination of respite providers may also be utilized with one providing day and one providing evening respite services. In utilizing such combinations of providers, one would need to consider their policies related to 24-hour respite care pay rates.

Limitations may also be imposed for minimal respite time. A provider should not be expected to spend two hours in transit to provide 30 minutes of respite care. In cases where the family is gone for less than an hour, the provider is usually paid a minimum of several hours service.

## EXAMPLE BUDGET

### PERSONNEL

Position	% Time	Cost	Subtotal	Grand Total
Project Director	10%	\$2,800		
Program Coordinator	100%	18,000		
Secretary	50%	4,300		
			<u>          </u>	
			\$25,100	

### CONSULTANT SERVICES

Subsidy for home respite providers	\$8,000	
Trainers	<u>1,000</u>	
		\$ 9,000

### TRAVEL

Local travel (to consumer homes, provider homes, coordinating the program, etc.)	\$600	
Out-of-town to visit other respite programs and professional meetings	<u>800</u>	
		\$ 1,400

### EQUIPMENT

Desk, chairs, trash cans, file cabinets, typewriter for two offices		\$ 2,500
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### SUPPLIES

Paper, supplies, xerox copying, etc.		\$ 600
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### OTHER

Postage, telephone, administrative overhead (accounting services, business office management, etc.), rent and utilities		<u>\$ 5,000</u>
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\$43,600

**Figure A**  
**Sample Fee Schedule for Respite Care Programs**

Program and Location	Pay to Provider			Cost to Consumer			Fee	Limitations of Service
	Hour	Day	Week	Hour	Day	Week		
Extend-a-Family Toronto	\$1	\$10		\$1	\$10		\$5	
Special Training for Exceptional Children, Billings, Montana	\$1-3	\$15 \$10 for school days		\$1	\$10-15			Families are allocated reimbursement allowance \$360/yr-one client \$300/yr-two clients \$240/yr-three clients you can not accumulate more than \$180 in reim- bursement credits at any one time
Archdiocese of Denver Denver, Colorado	\$1 min \$2-4 depending on degree of handicapping conditions	\$10 min \$15-20		\$1 \$2-4	\$10 \$15-20			
ARC Angel Acres New Iberia, La.					No Fees			Offered several times per month
Home Aid Resources Program Olympia, Washington	\$2.30- 3.30 Depending upon the number of handicapping conditions	\$15-20			Not Available			135 hours per year or 15 days per year Limit extended for single parent families or if a parent is also disabled.

Figure A (continued)

Program and Location	Pay to Provider			Cost to Consumer			Fee	Limitations of Service
	Hour	Day	Week	Hour	Day	Week		
Respite Foster Care Program Shawnee County, Kansas		\$12			\$1-17			30 days
Respite Care Program C. P. Center	\$2.50/hr plus \$.25 for each additional child	\$40			\$30 plus \$5 for additional child		\$5	
Oh What A Relief It Is Baltimore, Md.	\$3.50	\$30		Reimbursed on a sliding scale				10 days or 30 hours
Eastern Shore Respite Care Program Cambridge, Md.	\$2.90			Reimbursed on a sliding scale				
Respite Care Homes		\$8+\$100 a month for availability						Maximum 2 weeks per stay per client
Family Resources Program Baltimore ARC, Baltimore Maryland				\$1.50- 2.50	\$10			
Respite Care Program Montgomery Co. DSS Rockville, Md.	\$2.50	\$25		\$1.50	\$15			Maximum 28 days
Prince Georges DSS Hyattsville, MD.	\$1.50	\$15		\$1.50	\$15			
Respite Care Program St. Mary's DSS Leonardtown, MD.	\$2.00	\$18	\$100	\$2.00	\$18	\$100		

Figure A (continued)

Program and Location	Pay to Provider			Cost to Consumer			Fee	Limitations of Service
	Hour	Day	Week	Hour	Day	Week		
Maryland Society for Crippled Children & Adults, Hagerstown, MD.	\$1.50	\$12	\$60	\$1.50	\$12	\$60		Subsidies for the families of the mentally retarded
Respite Care Program Anne Arundel ARC Annapolis, Md.	\$1.50	\$15		\$1.50	\$15			

## APPENDIX G

### JOB DESCRIPTION AND PERSONNEL INTERVIEWING

Example of Job Description for In-Home Respite Care Program Coordinator

**Title:** Program Coordinator In-Home Respite Care Services

**Qualifications:** At least a bachelor's degree in human services with three or more years experience in providing community-based human services. Prefer master's degree in rehabilitation, social work, psychology, special education, or closely related human services field with one or more years prior experience in providing community-based human services. Knowledge of community-based human service programs and needs of families who have handicapped/disabled members is required.

**Responsibilities:** Will conduct and provide supervision of all operation aspects for in-home respite care services, including the following responsibilities:

1. Recruit, train, select and match home respite care providers.
2. Recruit, interview, set fees for, respond to, and match families with respite providers for in-home respite care services.
3. Maintain all records including financial data for the operation of the program.
4. Coordinate in-home respite care services with other community-based programs and agencies serving handicapped/developmentally disabled persons.
5. Present information regarding the in-home respite care program to the public and selected groups.
6. Plan, coordinate, and present information necessary to train in-home respite care providers.



7. Evaluate services and providers, and make necessary modifications on program under direction of agency director.

**Job Duties:** Will be administratively responsible to agency administrator and solicit input from in-home respite care advisory group, including the following job duties:

1. Recruit potential in-home respite care providers and families of handicapped developmentally disabled persons who require respite services.
2. Select provider trainees and provide training to them.
3. Upon request for in-home respite care service, match family and/or developmentally disabled person with respite care provider.
4. Maintain all necessary records including financial transactions and pay.
5. Make modifications to improve and expand services based on the program's operational data.
6. Coordinate in-home respite care services and family needs with other human service programs in the community.

**Salary:** Open

**Effective Date of Employment:** August 1982

#### **Pre-employment interviewing**

The purpose of the pre-employment interview is to decide whether the applicant will be able to do the job and whether he/she will fit into your organization. The interview should be a two-way communication to obtain information on the applicant's abilities, qualifications, and personality so that you will be able to make these decisions.

#### **Prior to the interview:**

- Decide exactly what competencies, qualifications, and personality traits you are looking for. Have a written job description ready which lists all job requirements and other particulars.
- Decide where to hold the interview. The surroundings should be formal yet relaxing. Because the applicant will be understandably nervous, you will want to insure privacy during the interview, and interruptions and distractions are not needed.
- Schedule the interview for a time that is mutually convenient, and be sure to allow enough time to discuss all aspects of the the job.

#### **Starting the interview and developing rapport**

The success of the interview will depend a great deal on the relationship you develop with the applicant:

- Let the applicant catch his/her breath
- Once the person is comfortable, get the him/her talking as soon as possible . Use well-prepared, open-ended questions. Encourage the applicant to talk freely and to volunteer complete and accurate information.
- Minimize your talking and concentrate on listening to what the applicant has to say.
- Don't waste time with questions that are not related to the person's ability to do the job or with questions which have been answered on the job application unless there are points which need clarification.

**Some suggestions for pre-employment interviews:**

- Because good interviewing skills are not inherent, you may wish to study a book on interviewing techniques.
- Prepare open-ended questions that require more than a yes or no answer from the applicant.
- Follow up written references with phone calls to previous employers. A number of standardized reference checklist forms are available for this purpose.
- In terminating an interview, IF you are sure that the candidate is acceptable and IF you have the authority to hire the applicant, be sure to discuss the possible starting date for the job.
- Become familiar with the Family Rights and Privacy Act of 1974.
- Interview questions *MUST* be non-discriminatory and job related. Be particularly careful when asking questions in the following areas:
  - Race, color, national origin, and religion
  - Sex, marital and family status
  - Education
  - Arrest and conviction records
  - Age
  - Availability for Saturday and Sunday work
  - Friends or relatives working for the company
  - Applicant's credit ratings
  - Physical requirements for the job
  - Experience

Specific guidelines have been established by the courts for questions in these and other areas. If you are not totally familiar with these guidelines, you may wish to read *Affirmative Action and Equal Employment: A Guidebook for Employers*, pages 40-43.

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## **IN-HOME RESPITE CARE PROGRAM DEVELOPMENT PROGRAM COORDINATOR'S MANUAL**

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## IN-HOME RESPITE CARE PROGRAM DEVELOPMENT

### *Section 1*

#### **The First Steps**

Introduction to Unit II

Community Resource Evaluation

Program Philosophy

Time Guidelines

The Core Planning Committee

Group Presentations

Since the information and activities in Unit I were designed to help a community decide whether it wants and needs an IHRC program, the preliminary planning has been accomplished, and the development and implementation of the IHRC program now rests primarily with the coordinator of the program. The information in Unit II addresses many of the planning areas and considerations which are necessary for the actualization of various program activities, functions, and techniques.

## *Section 1*

### **THE FIRST STEPS**

#### **Introduction to Unit II**

At this point, *YOU* are the single most important element of the respite care program. When the program has been established and operating, its services and experience will speak for you, but until that time, your community will be looking to you for information and answers. You will, of course, receive a great deal of help and support from your agency and the program advisory board/core planning committee, but the actual implementation of the program and its services is your responsibility. While this may seem somewhat overwhelming right now, the information in this unit is designed to help you through the step-by-step planning and actualization of the various activities and functions which are necessary for a successful program.

Interviews and consultations with various respite care programs and coordinators throughout the United States have indicated that the job of coordinator requires a personal sense of orderliness not required in many other professions. Addressing an issue too early or too late will have negative consequences for a program of this nature. If, for example, care providers are recruited and trained, and some are not given the opportunity to provide these services, providers may grow disenchanted and leave the program. Likewise, if the coordinator waits until the last few days prior to training to make arrangements for the training facilities or to line up guest speakers, the training may be inadequate, and trainees will not be ready to provide respite care services. Careful planning on your part will eliminate these and other possible problems, and the materials which follow are designed to assist you in careful, effective planning. (See also Unit I, Appendix B, p. 1.53 for additional program planning principles.)

The information in each section of this unit has been arranged to lead you through the various program-planning steps in an orderly, sequential fashion. Keep in mind, however, that many activities are concurrent (see chart, page 2.6) and must be planned accordingly.

1. When necessary, "*Notes to the Coordinator*" are included at the beginning of a section to introduce you to the overall purpose and scope of the activity (see "*Notes to the Coordinator*" for "*Recruiting Respite Care Providers*," page 2.19).
2. Certain activities, particularly those involving community contacts, require record keeping, and sample "*fill-in-the-blank*" forms are included with these activities. (See "*List of Human Service Agencies in the Community*," p. 2.21.) Please note that the number of blanks is in no way indicative of the suggested or required contacts you will be making. You will have to adjust these forms to meet the needs of your community and your program.
3. While it is suggested that you review all of the material in Unit I, specific references are made to various sections of that unit when appropriate.



## Community Resource Evaluation

Before any recruiting can be done (both consumer and provider) and before a training program can be formulated, you must make yourself fully aware of the resources available in your community. Suggestions are offered for various activities in this unit, but an overview must be established before any of these activities can be undertaken.

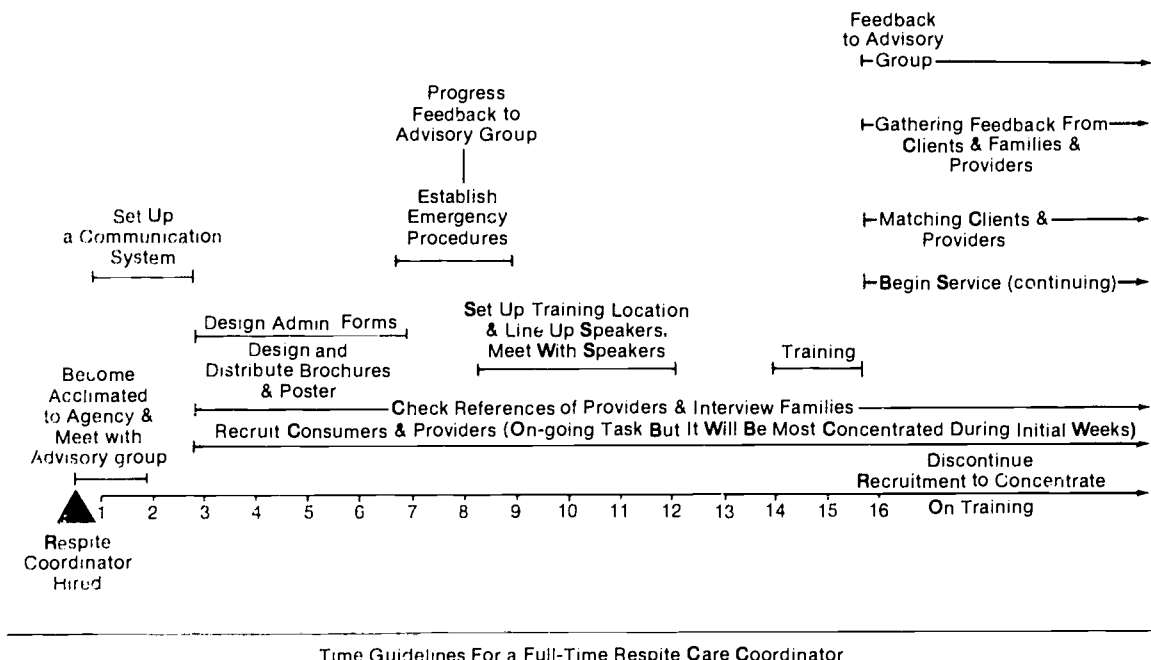
1. One of the most beneficial sources of information about the community will be the *CORE PLANNING COMMITTEE/ADVISORY BOARD*. You should review all of the steps which led to your hiring as program coordinator, and you should speak with the members of the committee about what avenues were used in recognizing the need for a respite care program in your community (See pp. 1.25-1.45).
2. Examine *THE COMMUNITY* itself to determine what resources are at your disposal. Is there a university, college, community college, or junior college in the community? If so, it will be helpful in recruiting, in the actual training program, and in a variety of other program activities. You should also check on churches, civic groups, etc., to see if they will be helpful for your program.
3. What *HUMAN SERVICE SYSTEMS* exist in the community? They may be helpful in establishing procedures and in answering any number of questions which may arise in the course of program planning.
4. *YOUR AGENCY* will be very helpful in preliminary planning. Through the agency, you can establish the strengths and needs of the human service network in the community, the possible sources of information and assistance for your program, and lists of contacts who will be willing to work with you and the program.

## Program Philosophy

In the course of promoting, publicizing, and recruiting for your program, you will be asked why a respite care program has been established in your community. Your response should reflect the general philosophy of your agency and the specific ideology of respite care itself. Although the philosophies of home respite care are simple and quite basic, they are often overlooked or misunderstood by those who have had no experience in caring for a child or family member with a handicap. You must stress that respite care services are a necessity and not a luxury if the families of the handicapped are to remain together and function as a unit. With no relief from the daily pressures they face, parents and family members often contract "burn-out syndrome," an exhaustion of physical and psychological resources which evolves after long and intensive periods of caring for a family member with a handicap (Sullivan, 1979). You should also emphasize that respite care, provided within the home, can relieve many of these pressures. These aspects should be considered when developing the basic philosophy that you will be presenting to the community.

## Time Guidelines

When you begin to consider all the responsibilities you face as program coordinator, they may seem numerous and confusing. The following chart has been prepared to illustrate the suggested sequence of events and activities that you should follow to maximize your effectiveness:



Time Guidelines For a Full-Time Respite Care Coordinator

You can see by this time chart that there are activities which, by their very nature, require some overlap; you do not have the luxury of addressing one specific aspect at a time. In some cases (as in the recruiting of care providers and consumer families), these activities will be of an ongoing nature. Activities such as training of care providers will only be addressed periodically. The frequency of these training sessions will depend upon your need for additional respite care providers.

To fulfill the varied responsibilities of the program, you must be flexible and able to deal with a variety of tasks simultaneously. Rarely will you spend an entire day concentrating on only one aspect of the program. Instead, you will be faced with the ongoing process of recruiting consumers and providers, setting up training facilities and sessions, and addressing local parent or civic groups, all within a single day. The ongoing nature of your responsibilities is represented by the overlapping lines of the time chart. Time frames, as you will note, have been suggested for each activity and are approximations based upon reports from experienced respite

care coordinators. While you must determine the schedule for your program, this chart indicates the sequence of activities and the approximate time required for each. Adjustments may be necessary for your individual program, and these adjustments may involve one or more of the following:

1. *Your employment status* (full-time vs. part-time). Adjust the time frames to adhere to your availability.
2. *Preliminary planning*. The extent of activities of the core planning group/ advisory board and sponsoring agency prior to your being hired will affect your time frames.
3. *The size of your community*. It may be easier, for example, in a large community to schedule speakers for your training sessions. However, activities such as publicizing the program and addressing civic groups may require more time.
4. *Clerical support*. A person to do office and clerical work can free you from the routine office responsibilities that can take up much of your time.

### **The Core Planning Committee**

The involvement of the core planning group should continue even after your employment as program coordinator. This core planning group, serving in an advisory capacity, can remain a vital facet of the overall program. You are strongly encouraged to utilize and to work with this group throughout the operation of the program. The members of this advisory group (See Unit I, p. 1.28) were selected because of their interest, expertise, and potential for ongoing support.

In addition, the advisory group can serve as a source of feedback which will be invaluable to you. In their capacity as administrators of other agencies and programs, and through their involvement with families of the handicapped, the members of this board will get information from the community about your program, information which otherwise might not be communicated to you. Remember that the advisory group can be more than a spring board for the implementation of the program.

### **Group Presentations**

You will frequently be called upon to speak before parent groups, civic and fraternal organization, college classes, church groups, etc. These presentations are particularly important as the program is being established; respite care is a new concept and will require a great deal of explanation. In developing presentations for the above mentioned groups, you may want to include one or more of the following:

1. *Public awareness and education* let your community know about the program and the services available. Many people will be totally unfamiliar with respite care and the variety of services offered by the program. Remember that word of mouth will eventually be your strongest source of publicity.

2. *Recruiting providers* must be an ongoing process that should not stop when you have signed up enough trainees for the first training session. As the program grows, you will need additional providers to meet the increasing demand for the services of your program (see pp. 2.17-2.33 of this Unit).
3. *Recruiting consumers* is also an ongoing process. Even though you may not be addressing individuals with a family member who is handicapped, audience members may have friends, neighbors, and relatives who are in need of your services (see pp. 2.35-2.39 of this Unit).
4. *Requests for funding* for your program should be an ever-present consideration (See Unit I, pp. 1.18-1.21), and these requests must be carefully planned. Many of the organizations that you will be addressing are inundated with similar funding requests, so contact the president or group leader and ask if the soliciting of funds would be appropriate.

Prior to addressing any group, you should consider which of the above goals you wish to achieve. Rarely will you be concerned with only one goal (such as recruiting care providers); more likely you will address several of these goals simultaneously during each presentation.

The information presented thus far will better prepare you to read the following sections and to formulate your own plans for *your* respite care program. Each of the following sections deals with a single aspect of the program plan and contains guidelines and suggestions designed to assist you in coordinating that particular aspect into the total program. It is advisable that you periodically refer to the time chart (p. 2.6 of this Unit) so that you will address each aspect of your program in its proper sequence.

## **IN-HOME RESPITE CARE PROGRAM DEVELOPMENT**

### *Section 2*

### **Establishing a Communication System**

Since much of the planning, coordination, and operation of the IHRC program will be done by telephone, an effective, efficient communication network is a necessity. The information in this section is designed to offer some practical suggestions to help you establish just such a system—one which will work for your individual program.

## Section 2

### ESTABLISHING A COMMUNICATION SYSTEM

You will be coordinating a variety of activities for the respite care program, and trainees, care providers, families, community agency personnel, and others should be able to contact you if a question, problem, or particular need should arise. Because these matters often require immediate attention, and because your job responsibilities include many hours away from your office, an effective communication network should be established for the program as soon as possible. The following suggestions are designed to assist you in setting up just such a system.

A *CHAIN OF COMMAND* should be established as soon as possible. Such a system may already exist within your agency, and the communication network for the IHRC program might easily be adapted to these methods which are already in operation. Once the respite care program has been in existence for some time, you may also have some care providers who are reliable enough to assist you with some of the clerical aspects of the program and who can be contacted for basic program information when you are unavailable. This will, however, depend on the employment status of the care providers. You may also have to rely on other agency personnel for assistance. In any case, always have available the name and phone number of someone who can answer questions in your absence, and be sure to leave a phone number where *YOU* can be contacted in case of an emergency.

You may also want to keep some type of *ROSTER OR CARD FILE* which lists the names of care providers and any other *nonconfidential* information about the program. Just exactly what information is confidential and should not be kept in this file or roster will be determined by the guidelines established for the program and by who will have access to this information in the file or roster.

If funds are available, A *TELEPHONE ANSWERING MACHINE* can be one of the most effective aids in a communication network or system. With such a device, you will never be completely out of touch with those needing assistance or information. You should also make it a point to answer all calls promptly. Consumers, care providers, and those interested in the program will stop using the answering system if calls are not returned as soon as possible. You may also want to maintain a telephone log for all incoming and outgoing calls. This log can provide you with valuable information for future planning and reference.

The following are some cautions that should be considered when you are establishing your communication system:

1. Be prepared for some fairly large telephone bills if your area requires long distance calls to provide service to all persons requesting respite care. Check into all telephone service options in your city or area.
2. While striving to be as responsive as possible, do not expect to provide service for all last-minute requests. With the exception of emergency situations, encourage client/consumer families to plan activities as far in advance as possible.
3. Remember that first impressions are extremely important, especially when you are just beginning the program. Very often the first contact care providers and consumers have with the program will be by telephone. Make a good impression: be a good listener, be courteous, be factual, and be prompt in returning calls.

## IN-HOME RESPITE CARE PROGRAM DEVELOPMENT

### *Section 3*

#### **Fees**

### *Section 4*

#### **Legal Issues**

Two of the most variable facets of an IHRC program are those involving legal issues and the establishment of fees to be charged for respite care services. Agency regulations as well as state and federal laws must all be taken into consideration when you are determining policies for your program.



### *Section 3*

#### **FEES**

A review of respite care programs throughout the United States determined that most charge a fee to the client/consumer family for respite care services provided. While most agencies provide a sliding fee scale, the general fee schedules vary from program to program. Frequently the final decision on fees will be made by your agency, but you should be informed about not only what the fees are, but how they were determined. This will assist you in answering any questions that clients/consumer families may have about the fees they will be paying. For information that will assist you in evaluating needs and determining fees to be charged for the program, see Unit I, pp. 1.80-1.81.

### *Section 4*

#### **LEGAL ISSUES**

Legal issues in the area of respite care are very complex, and it is not possible for a training manual to provide all the legal information you may require. Some questions did become evident in the course of reviewing respite care programs, and these questions are outlined for you in Unit I, p. 1.49 of this manual. These questions can suggest other areas you will need to explore for your program. It is recommended that you seek the advice of an attorney in your community about specific matters.

## **IN-HOME RESPITE CARE PROGRAM DEVELOPMENT**

### *Section 5*

### **Recruiting Respite Care Providers**

Notes to the Coordinator

What to Look for in a Respite Care Provider

Determining the Number of Providers

Methods of Recruiting Providers

Activities

Reference Checks

Qualified care providers are the foundation of a successful IHRC program; without them, no program will exist. The information and activities in this section are designed to help the program coordinator recruit and screen individuals who will be going through the training sessions described in Unit III of this manual.

## *Section 5*

### **RECRUITING RESPITE CARE PROVIDERS**

#### **Notes to the Coordinator**

As program coordinator, you are charged with the responsibility of recruiting quality respite care providers, and the employment status of these providers should be clear to you before you begin recruiting. Will they be unpaid volunteers or paid volunteers? Will they be paid employees of your agency? In some instances, providers are considered as agents of the parents and not employees of the sponsoring agency. Factors such as these may influence your recruitment efforts.

There are no "typical" respite care providers. They range from the high school student to the elderly, retired person; they come from all socioeconomic, occupational, religious, and other demographic groups. Some are the parents or siblings of a person who is handicapped, while others have had no previous contact with people who are handicapped. Do not overlook anyone as a potential provider when you begin recruiting.

### **What To Look For In A Respite Care Provider**

Although it is impossible to characterize an "ideal" respite care provider, some important qualities can be identified:

1. ***SENSITIVITY***—the respite care provider must have an understanding of the needs of both the clients and their families.
2. ***COMMON SENSE***—the respite care provider must be able to react quickly and effectively in both routine and emergency situations.
3. ***PERSONAL RESPONSIBILITY***—the respite care provider must keep all scheduled appointments and follow the directions of the parents. He/she should show respect for the property of the family when working in the home.
4. ***KNOWLEDGE OF SELF-HELP SKILLS***—can the potential care provider perform the everyday household tasks and responsibilities that will be required of him/her (such as cleaning, cooking, etc.)?

### **Determining The Number of Providers**

In determining the number of care provider trainees you want to recruit for a training session, you may wish to consider the following:

1. The number of consumer families you will be serving should be estimated. This will, of course, depend upon the size of your community, geographic considerations, number of requests you have received from interested families, etc.
2. The number of persons expressing interest in the training will exceed the actual number of providers who complete the training. Some trainees may quit the program, and, upon occasion, you yourself may choose to drop an individual from the training.
3. The facility you use for your training may limit the number of trainees; you must determine how many trainees the room will accommodate.
4. The program will need enough providers to meet ***ALL*** requests for service. If a family is refused respite care one time, they may not seek your services again.
5. The program must not have too many providers. If there is an excess number, some will not be afforded the opportunity to work and may eventually lose interest in the program.
6. The recruiting of providers is an ongoing process. You will be offering training sessions periodically, and you want to keep the recruiting process in motion at all times. Look over the list of recruiting activities (pp. 2.21-2.33) and determine which are best suited for ongoing recruitment. For example, you may want to keep your newspaper ad (see p. 2.25) running at all times if such a move is effective and economical. Interested persons can be told that the training program will not start until sometime in the future, and that you will place their names on a list and notify them prior to the beginning of that session.

## Methods of Recruiting Care Providers

The following activities have been used by other in-home respite care programs to recruit care providers. The activities you will employ in your community will be based upon your philosophy, the type of community (rural or urban) you will be serving, the resources currently available in your area (e.g., the presence of a large college population), time and financial resources available to you and your agency, existing human service programs in your community, and a volunteer service coordinating agency. You may have to modify some activities even further to fit your own program.

The format for this section includes methods of recruitment and forms to be used in making notes, records of contacts, and results of these contacts. This format was chosen to offer you a comprehensive array of methods of recruiting, and the recording spaces following each method can serve as a permanent record of the effectiveness of the various recruiting methods.

### Activities

1. **HUMAN SERVICE AGENCIES** such as agencies of rehabilitation services, health, etc., may be valuable sources of respite care providers as well as consumers. Employees of these agencies, many of whom have already had experience and training in working with people who are handicapped or developmentally disabled, may wish to "moonlight" as respite care providers. These agencies may also have a listing of volunteers or potential volunteers which they might be willing to share with you. Former employees or people seeking employment in these agencies may also be potential care providers. To find out if there are such agencies operating in your community, contact the local United Way office, the public library, or consult the telephone directory. You will also want to talk with experienced colleagues in the human services field.

#### LIST OF HUMAN SERVICE AGENCIES IN THE COMMUNITY

Agency	Contact Person	Telephone	Date
<hr/>			
Results: <hr/>			
<hr/>			
<hr/>			
Results: <hr/>			
<hr/>			
<hr/>			

LIST OF HUMAN SERVICE AGENCIES IN THE COMMUNITY

Agency	Contact Person	Telephone	Date
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Results: _____			
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Results: _____			
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Results: _____			
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Results: _____			
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Results: _____			
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Results: _____			
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Results: _____			
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2. *ADDRESS CLASSES* in local universities or community colleges. Professors in education, special education, psychology, sociology, social work, speech pathology, rehabilitation, etc., may be the most responsive to your requests to address their classes. When addressing college students, you might include: a) the social importance of the work; b) the valuable learning experience derived from working with handicapped individuals; c) the work experience which can be listed on resumes or graduate school applications; d) payment for services; e) flexibility of work hours.

#### LISTS OF CONTACTS IN LOCAL COLLEGES

College & Department	Contact Person	Telephone	Date
_____			
*Results: _____			
_____			
_____			
*Results: _____			
_____			
_____			
*Results: _____			
_____			
_____			
*Results: _____			
_____			
_____			

\*Under results you may want to include planning details such as the date of presentation, the time and place, possible materials to be handed out, audio-visual equipment needed and available.

3. *ADDRESS CIVIC GROUPS*, fraternal organizations, local government (town boards, etc.), parents' associations, and local professional groups or organizations. These presentations may follow the same basic format as your address to college groups. An additional benefit that may result from this type of address might be increased local support for your program in the form of publicity, funding, physical space (for meetings and training sessions), and political support. These groups may be located with the assistance of your public library or through your telephone directory.

#### LIST OF LOCAL CIVIC GROUPS

Group	Contact Person	Telephone	Date
_____	_____	_____	_____
_____	_____	_____	_____
*Results: _____			
_____			
_____			
*Results: _____			
_____			
_____			
*Results: _____			
_____			
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*Results: _____			
_____			
_____			

\*Under results you may want to include planning details such as the date of presentation, the time and place, possible materials to be handed out, audio-visual equipment needed and available, etc.





5. Ask for the opportunity to talk to *RELIGIOUS ORGANIZATIONS*. Many churches and synagogues have youth and senior citizen groups which are involved in public service projects. Members of these groups may be interested in becoming care providers themselves or may know someone else who may be interested. Most of these organizations publish weekly bulletins, and many publish monthly newsletters. An announcement in one of these publications will reach potential care providers as well as consumer families. Listings of churches and synagogues and names of pastors and rabbis can usually be obtained from the Chamber of Commerce or Visitors' Information Bureau in the community or in the Yellow Pages of the phone directory.

#### LIST OF RELIGIOUS ORGANIZATIONS IN THE COMMUNITY

Religious group	Pastor/Rabbi	Telephone	Date
Results: _____			
_____			
_____			
Results: _____			
_____			
_____			
Results: _____			
_____			
_____			
Results: _____			
_____			
_____			

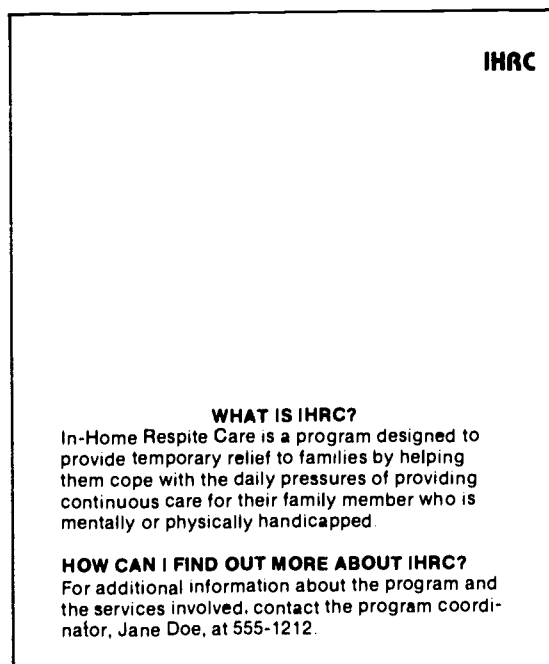
6. **POSTERS AND BROCHURES** which explain your services can be printed and distributed in public places. This method has been used by nearly every existing in-home respite care program. (Samples of both follow.) In most cases, agencies have chosen to make the brochures and posters very simple in format with little or no art work, an approach which minimizes the cost of printing.

You might consider a more professional brochure of high artistic quality if you are able to find someone with talent to contribute the art work. Art students or teachers from the local high schools and/or university might be willing to help. A teacher in a school's art department may help by assigning the poster or brochure as a class project, and local artists or advertising agencies will sometimes donate their talents.

If you have established a priority for recruitment of providers in your community (college students, human service agencies, etc.), you should try to select distribution places where these prospects gather, wait in line, or generally have the time to read posters and brochures.

Several possible locations to leave brochures might include the public library, the university center of your local college, unemployment offices, hospitals, social service agencies, doctors' offices, banks, post offices, schools (elementary and high school), town halls, YMCA and YWCA, motor vehicle offices and laundromats. The listing of possible places to distribute your posters and brochures is limited only by the size of your community and your imagination. As a policy, it is not advisable to leave material without getting the permission of the owner, manager, or whoever is in charge of the facility in question.

If you plan on printing different posters and brochures for recruiting consumers (as opposed to providers), the placement of the materials may also vary.



An appointment with the doctor? A night out at the movies or dinner? A weekend outing or a week's vacation? Are these routine activities for you and your family?

For many of us they are, but for families with a member who is physically or mentally handicapped, they are infrequent if not impossible privileges. WHY? Because these families are unable to find adequate, qualified care for their family member who is handicapped. But IHRC services are now available in the community to help solve this problem.

**WHAT IS IHRC?**

In-Home Respite Care is a program designed to provide temporary relief to these families by helping them cope with the daily pressures of providing continuous care for their family member who is mentally or physically handicapped.

**HOW DOES THE IHRC PROGRAM WORK?**

IHRC services are provided in the family's home. On a pre-arranged basis, qualified care providers, men and women who have been trained to provide these services, will come to the home and care for the handicapped family member while other family members are away. Services are available on an hourly, daily, or even weekly basis.

**WHO IS ELIGIBLE FOR IHRC SERVICES?**

Any family caring for a child or adult who is physically or mentally handicapped can use IHRC services.

**HOW CAN I FIND OUT MORE ABOUT IHRC?**

For additional information about the program and the services involved, contact the program coordinator, Jane Doe, at 555-1212.

7. **VOLUNTEER COORDINATING AGENCIES** often have lists of people seeking volunteer work. They may also be agreeable to listing your agency and program. Another source for locating potential volunteers might be the local United Way office. They may have been in contact with individuals or groups interested in working with the handicapped.

8. Radio and television stations are required by law to provide some **PUBLIC SERVICE ANNOUNCEMENT (PSA)** time, and nonprofit organizations such as IHRC programs are eligible for PSA time at no charge. When writing for broadcast radio or television, the following rules apply:

1. Simple, declarative sentences best catch the listener's attention.
2. Round off all statistics and numbers for easier comprehension.
3. Precede all quotations with the source, but avoid all direct quotations if possible.
4. Personalize. You are writing for the ear, not the eye.
5. Avoid long descriptions which may be tedious and which can lose your audience.
6. Avoid hackneyed expressions and cliches. They can be very annoying to the listener.

Contact the stations in your area to see if they want only written copy or if you will need to submit prepared tapes and slides with the copy. Copy should be typed and triple spaced on one side of an 8½ × 11 page. A thirty-second spot will require about seventy-five (75) typewritten words. The name, address, and phone number of the person to contact for more information should be stated at the top of the copy.

Be sure to include the 5 W's: Who, What, When, Where, and Why. If the agency name and phone number appear in the copy, they should be mentioned at least twice so that people will be sure to hear that information.

Guidelines for radio and television PSAs:

1. Include a very simple definition of the type of service being provided. For example, "(Agency name) is now offering a program of trained personnel who will come into your home to care for your family member who is handicapped." Make these statements as brief and simple as possible.
2. Direct your PSAs at the exact audience you are looking for. When recruiting for providers, for example, you may state that "anyone interested in earning extra money and providing a much-needed service to the community should contact (coordinator's name) at (phone number)." If you are recruiting consumer families, you might want to say "(Program name) is now offering in-home care respite for persons who are developmentally disabled."

3. You may want to include a statement of cost. For example, "there is no charge for the training which can be completed in four sessions." For consumer families you might want to explain that "fees for this service are based on a sliding scale and, depending on your income, range from (lowest rate) per hour to (highest rate) per hour."
4. Your announcements to recruit providers should be aired well in advance of the training sessions. Advertising too soon or too late will be of little benefit in recruiting. Contact the radio and television stations to find out about any lag time in airing PSA's.
5. Have your PSA's read on several different radio and television stations. You might also consider placing your announcements on a foreign language station if the ethnic population of your community is diverse.

#### LIST OF LOCAL RADIO AND TELEVISION STATIONS

Station	Contact Person	Date Announcement Sent	Dates Aired
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Results: <hr/>			
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Results: <hr/>			
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<hr/>			
Results: <hr/>			

9. *TELEVISION AND RADIO TALK SHOWS* are often interested in interviewing local people from public service agencies. This form of advertising is free of charge and gives you an opportunity to reach a larger segment of the community. By contacting your local TV and radio stations, you may be able to gain an invitation to appear as a guest on one of these talk shows.

LIST OF TV AND RADIO STATIONS WITH TALK SHOWS

Station	Contact Person	Phone	Contact Date	Appearance Date
---------	----------------	-------	--------------	-----------------

Response: \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

Response: \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

Response: \_\_\_\_\_

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\_\_\_\_\_

Response: \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

Response: \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

Response: \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

10. *PARENTS OF INDIVIDUALS WHO ARE HANDICAPPED* can refer you to people who are experienced in caring for handicapped persons and who may wish to receive additional training and possibly earn some extra money.
11. *GROUPS OF RETIRED PERSONS* are often seeking opportunities to spend their time in a productive manner. In many communities, "Foster Grandparent" programs have been developed where people spend several hours a week visiting with children in institutions. These people are usually given a small stipend, travel expenses, and/or lunch in return for their services. The programs have shown that these "foster grandparents" are very capable of caring for a person who is disabled. This segment of the population should not be overlooked as potential respite care providers.

#### LIST OF LOCAL SENIOR CITIZEN GROUPS

Group	Contact Person	Telephone
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Results: <hr/>		
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### Reference checks

These suggestions are designed to assist the program coordinator in making a decision about accepting a potential care provider into the training program:

1. The coordinator should review the application and reference process of the agency, making sure to adhere to all agency policies and procedures.
2. At the time the prospective care provider completes an application and/or is interviewed, the coordinator should obtain the names, addresses and telephone numbers of the applicant's personal references, and present and former employers.
3. If the application does not state that references will be checked, the coordinator should have the prospective care provider give written consent for the contacts to be made.
4. Contact the references. The coordinator may wish to request a letter of recommendation, the completion of a reference form, or may request information over the telephone.
5. Considerations which should be covered regardless of your reference check procedure include:
  - a. How long have you (the person given as a reference) known the applicant?
  - b. What is your relationship with the applicant (employer, teacher, etc.)?
  - c. What are your impressions of the applicant's:
    - patience
    - punctuality
    - responsibility
    - dedication
    - ability to follow instructions
    - interest in working with the handicapped
    - ability to react in an emergency situation
    - general health
    - motivation
6. Provide an explanation to the applicant as to the scope of the reference check (this will vary depending on agency policies, the number of applicants, and your preferences). Usually references will be obtained from two or more sources in order to formulate a more accurate picture of the prospective care provider.

## IN-HOME RESPITE CARE PROGRAM DEVELOPMENT

### *Section 6*

### **Recruiting Consumer Families**

Notes to the Coordinator

Methods of Recruiting Consumer Families

Five Common Questions of Potential Consumer Families

In spite of the obvious need for respite care services, community IHRC programs throughout the United States have experienced a strong hesitancy on the part of families to use respite care services, particularly when a program is new to the community. To overcome this obstacle, the information and activities in this section are designed both to help the program coordinator recruit consumer families and to answer their questions and alleviate their initial concerns about the program. Without consumer families, there is no need for IHRC services in the community.

## *Section 6*

### **RECRUITING CONSUMER FAMILIES**

#### **Notes to the Coordinator**

No matter how essential the respite care program may be in your community, many parents will be reluctant to use your services, especially when the program is just beginning. Many new respite care programs have reported an initial disparity in the number of service providers and the number of consumer families. Remember, you will be dealing with parents who may have never left their child with anyone other than a member of the immediate family. Other parents have never left their child with anyone at all. Some families will have tried services similar to in-home respite care with little or no success, while others will want to wait until your program has "proven" itself. These attitudes are not at all uncommon.

Since you will be making the initial contacts with consumer families, you must be able to provide them with both the specific information they will need and the emotional support they will be looking for. **DO NOT DEAL ONLY WITH FACTUAL DATA;** listen carefully to the feelings and concerns these families will be expressing about the idea of leaving their family member with a "stranger."

### **Methods of Recruiting Consumer Families**

The methods you use to recruit consumer families, like most other aspects of the program, will be ongoing and will run consecutively with other activities (see chart, page 2.6). Many of these recruiting procedures will be very similar to those described on pages 2.21-2.33, and one method will often yield both consumer families and providers. A poster in a supermarket, for example, may attract inquiries from both potential consumers and providers. The following list is presented primarily for recruiting consumer families. Review these suggestions and decide which can effectively be combined with activities from "Recruiting Providers" in Section 5. You will also want to keep accurate records of these contacts, and you may want to use contact forms similar to those found in Section 5.

1. *POSTERS AND BROCHURES* should be placed in strategic areas where the families of handicapped persons will be likely to see them: schools, physicians' offices, churches, etc. Samples of posters and brochures can be found on pp. 2.27-2.28.
2. *PUBLIC SERVICE ANNOUNCEMENTS* (see page 2.29)
3. *LOCAL RADIO AND TELEVISION TALK SHOWS* (see page 2.31)
4. *LOCAL NEWSPAPERS* are usually interested in articles about human service programs. This type of information is usually included in the Sunday supplement and/or "Family News" sections of the paper. Contact your local newspapers for specific details on how to get your program publicized in papers.
5. *COMMUNITY AGENCIES AND REHABILITATION SERVICES* are logical contacts for you to make. Parents with a mentally retarded child, for example, may contact the local ARC chapter if they are looking for information about services which are available. Stay in close contact with the human service agency network in your community (see pp. 2.21-2.22).
6. *CIVIC GROUP* (see page 2.24) contacts should be maintained and updated continuously. Make presentations to local professional, civic and/or social groups (Lions, Knights of Columbus, Rotary Clubs, Jaycees, etc.), and maintain contact with community leaders (clergy, PTA members, school principals, teachers, physicians, etc.). Keep accurate records of these contacts.

## **Five Common Questions of Potential Consumer Families**

### ***HOW WAS THIS PROGRAM DEVELOPED?***

Explain to parents that the program resulted from a community assessment survey which indicated that in-home respite care was needed in the community. Further explain that the approach used to formulate the program has been based on the experiences, both successful and unsuccessful, of in-home respite care programs throughout the country.

### ***WHO ARE THE CARE PROVIDERS?***

Explain that care providers are carefully-screened individuals who have been trained for respite care provision in such areas as first aid, CPR, behavior management, etc.

### ***HOW WILL THE CARE PROVIDER KNOW THE CHILD'S SPECIAL NEEDS?***

In addition to being trained in the basics of in-home respite care, providers will be required to spend some time with the parents, family members, and child for individualized training prior to the provision of services.

### ***HAVE OTHERS USED THIS SERVICE?***

If there are families who have used the services of the program and who are willing to discuss their experiences with potential consumers, you might have these "experienced" families contact those who have questions about the program. An informal reception at the end of a training session may be the ideal time for such a get-together.

### ***WHAT IS THE CHARGE FOR THE SERVICE?***

The answer to this question will, of course, depend on the fees determined by your agency (see pp. 1.80 and 2.15), but you should be informed about not only what the fees are, but how they were determined and how the sliding fee scale works.

A majority of the parents who have been interviewed about respite care indicated that they would feel more comfortable with the idea of in-home respite care if they were given the opportunity to observe the care provider interacting with their family member prior to the first actual respite. If possible, you should arrange to have the provider come to the home and work with the handicapped individual for a limited period of time (one or two hours) while the parents and other family members are at home. Parents could go about "routine" activities while the provider engaged the handicapped family member in activities similar to those which might be used during the respite care interval. In this way, both the parents and the child could evaluate the experience, the provider could receive some supervision from the parents and gain necessary information about the handicapped individual. After such an experience, the first respite care visit would not be as potentially traumatic for the parents, the child, and the care provider.

## IN-HOME RESPITE CARE PROGRAM DEVELOPMENT

### Section 7

#### Matching Consumers and Providers

The matching of consumer families and care providers is one of the most crucial concerns of any IHRC program. Not only must you know your clients and providers well, you must also use intuition, common sense, and your experience to determine which matches will and will not work best. The information in this section is designed to assist you in making these important decisions.

## Section 7

### **MATCHING CONSUMERS AND PROVIDERS**

The purpose of this section is to offer the respite care coordinator some strategies to be used to match care providers with consumer families. A successful match should be evaluated from the perspectives of the client, consumer family, and the care provider. When all three report a comfortable, restful, incident-free experience, you may consider your match successful.

The matching procedures of various in-home respite care programs were reviewed, and it was found that most coordinators relied chiefly upon their intuition and experience to make matching decisions. Consider the following strategies before arranging the placement of a respite care provider with a consumer family:

1. *Eliminate obvious mismatches.* It is a simple process to decide who will NOT make a good match. For example, a family may indicate a preference for a provider who is of a particular race, age, or sex. In interviewing parents and providers, get as much of this type of information as possible; the more you know about such preferences, the fewer will be the number of mismatches. Any inability to meet stated preferences should be explained to families prior to formalizing the respite agreement. The parents should be given the option of continuing the respite as planned or waiting until a care provider of their preference is available.
2. *Know your clientele.* You should be aware of the physical condition and behavior of respite care clients and providers. Placing a new provider in the home of a person with a handicap with particularly difficult behavior problems or matching a ninety-five pound female provider with a 220 pound man who needs to be lifted from his bed and carried to his wheelchair would be obvious mismatches.

3. *Try to rematch.* It is good practice to place providers into homes where they have previously worked, particularly if parents have requested their services again. This gives the provider the advantage of being familiar with the client, the family, and the home. It also spares the family the necessity of "retraining" a different provider for each respite service. Most importantly, it allows the client the opportunity of establishing a rapport with the care provider.
4. *Watch for hesitancy or resistance.* If you sense hesitancy on the part of client, family, or provider concerning a proposed match, it is advisable to assign another provider for the particular respite. For whatever reasons, the wishes of both providers and consumers should be honored, but the resistance or hesitancy should be explored to assist in planning future matches. Strive to make providers and consumers honest in their evaluations of the matches in which they are involved.
5. *Be aware of transportation needs.* Knowledge of a provider's transportation situation will enable you to make decisions regarding matches. In some cases, the provider may not be able to get to a certain location because of lack of transportation, and you should know this before considering a provider-client match.
6. *Know the provider's location preference.* Determine in advance the geographical areas in which a provider will or will not work, and make every effort to honor these preferences.
7. *Be aware of other restrictions.* Familiarize yourself with any other restrictions providers might place on potential respites: how late they wish to or can work, days they are available to work, type of handicapped person with whom they prefer to work, etc.

These guidelines may seem restrictive and confusing, but most coordinators agree that this process becomes somewhat intuitive. The guiding philosophy which should prevail in matching decisions should be the provision of quality care to your clients, and you must make every possible effort and consideration to see that such care is provided.



## IN-HOME RESPITE CARE PROGRAM DEVELOPMENT

### Section 8

#### **Program Administration**

Notes to the Coordinator

Forms

Record Keeping and Filing Systems

Overall Program Control

The IHRC program, because of its very nature, will require extensive paperwork and record keeping. The information in this section gives basic administrative suggestions as well as recommendations for forms to be used for the program, possible filing systems, and record keeping, all of which are designed to simplify the paperwork and necessary administrative work as much as possible.

## *Section 8*

### **PROGRAM ADMINISTRATION**

#### **Notes to the Coordinator**

If your program is affiliated with a large agency, some of the information in this section may not be applicable. But if the program is new and is associated with a parent organization or other group with few established procedures, you will want to incorporate the following information and suggestions into your program format.

#### **Forms**

Depending on the procedures which are used by your agency or those which you yourself establish, you will need a number of different forms for various aspects of the program. Some of these will be standardized forms (time sheets, employment applications, W-2 and W-4 forms, etc.) which are generally available through any office supply outlet or which are already used by your agency. Other forms, however, must be specifically designed for the respite care program, and six basic forms are included in this section. Each is designed to elicit specific information from both consumer families and care providers. These forms may be reproduced as they are printed in this manual, or you may wish to adapt them to fit the individualized needs of the program. In either case, it is suggested that you print only a limited supply of forms; you may want to change or adjust these forms, based on your experience with them, as the program progresses, and you do not want to have an excess of forms on hand if you do so.

1. The *RESPITE CARE REGISTRATION FORM* contains information about the client and the consumer family in four general areas:

1. General consumer family information
2. Client information: handicapping condition, abilities, skills, and special problems
3. Medication information
4. Emergency procedures, contacts, and information

The information from this form will assist you in matching consumer families and care providers (see p. 2.43), and providers will use this information during the actual respite period.

As the program grows and gains acceptance in the community, your methods for completing this form may change; the information may be obtained over the telephone, or you may allow experienced care providers to obtain the information from the family. But until the program has been firmly established, it is strongly suggested that you, the coordinator, visit the home of each consumer family and fill out the form with the family. Not only will this give you valuable experience in obtaining information, experience which you can pass along to care providers in later training sessions, but it will also help to reassure the consumer families who are unfamiliar with the concepts and procedures of the respite care program.

When interviewing the family, pay attention to the concerns and feelings which they express. Begin the interview by trying to understand the family's perspective on caring for the client. Obtain information on what the client likes to do and is able to do well (positive aspects) as well as his/her special problems or needs. Use open-ended questions; if you need more specific information, you can ask for it later in the interview. You should also make it clear to the family (and later to the provider) that the information on the form will be used only as a reference. Exact procedures and directions on caring for the client will be obtained by the provider when he/she comes to the home for the actual respite care period.

2. You may find some reluctance or hesitation on the part of parents/guardians to sign the *GENERAL RELEASE FORM*. For this reason, it is advisable that you, as program coordinator, have the family complete and sign this form rather than sending the form with the care provider for the family's signature at the time of service provision. If you have the parents sign this form when they fill out the registration form, you will be able to answer any questions the family might have about the release. This form gives the care provider permission to take the client in his/her car if travel is "absolutely necessary" during the respite period. In addition, the form releases the provider, the program, and the agency from any liability for accidents or incidents which might "adversely affect the health, safety, or welfare" of the client. If your agency has not already done so, you should seek legal advice on this and all release forms.

3. The care provider should have the family complete and sign the *AUTHORIZATION TO ADMINISTER MEDICATION* form at the time of service provision. This form gives the provider permission to administer medication to the client, and it lists the types of medication, the dosages, and the frequency and time of administration. Remind the care provider that this form is a reference form. He/she should not only get specific instructions from the family, but he/she should also ask for a demonstration from the parents or guardians on just how the medications are to be given.

It is important that you explain to the family that this form and all other forms and procedures which refer to "emergency" situations are precautionary measures which are taken in the event that such a crisis situation might arise. You should reassure the family that such situations are the exception and not the rule, but that you want the care provider to be prepared for any situation that might come up during the respite period.

Under certain circumstances, the family may not want to sign these forms. If, for example, the parents or guardians will only be next door or across the street for the evening, they may wish to be notified in case of an emergency, and they may return to the home to handle the situation. In such instances, you should have the care provider make a notation to that effect at the bottom of the form. If the client is taking some type of medication, but there will be no need for the provider to administer that medication during the respite period, he/she will also want to make note of that on the medication form.

3. The *CLIENT/CONSUMER FAMILY RESPITE CARE EVALUATION* form should be completed by the family after respite care services has been provided. Encourage the family to be as honest as possible in evaluating both the services and the provider (see p. 2.61).

5. You should also have the care provider complete the *CARE PROVIDER EVALUATION FORM* which gives his/her overall impression of the service provision. Again, you should encourage complete honesty since you will be using both of these evaluation forms for future matching and reference (see p. 2.63).

6. The *CARE PROVIDER INFORMATION* form is a quick-reference sheet designed to give you basic information about the provider, his/her availability, and any preferences or limitations on service provisions.

## RESPIRE CARE REGISTRATION FORM

Parent/guardian names \_\_\_\_\_

Address \_\_\_\_\_ Phone \_\_\_\_\_

Specific directions to the home \_\_\_\_\_

Family will pay \$ \_\_\_\_\_ for respite service as negotiated From sliding scale  
information: IHRC program will pay \$ \_\_\_\_\_

Pay procedures as negotiated are \_\_\_\_\_

Client's name \_\_\_\_\_ Nickname \_\_\_\_\_

Age \_\_\_\_\_ Weight \_\_\_\_\_ Height \_\_\_\_\_

What is the client's handicapping condition? \_\_\_\_\_

What are his/her strengths/what can he/she do well? \_\_\_\_\_

What does he/she particularly enjoy doing? \_\_\_\_\_

What activities might he/she enjoy doing with the care provider?

What are his/her needs or assistance requirements? \_\_\_\_\_

When does he/she need supervision? \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

Are there particular instructions for any of these? \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

What are his/her strengths and needs in the following areas:

Communication \_\_\_\_\_

\_\_\_\_\_

Feeding \_\_\_\_\_

\_\_\_\_\_

Mobility \_\_\_\_\_

\_\_\_\_\_

Toileting \_\_\_\_\_

\_\_\_\_\_

Dressing \_\_\_\_\_

\_\_\_\_\_

Sleeping \_\_\_\_\_

\_\_\_\_\_

Other \_\_\_\_\_

\_\_\_\_\_

Personal/interpersonal behavior strengths and needs \_\_\_\_\_

\_\_\_\_\_

At home \_\_\_\_\_

In public \_\_\_\_\_

Are there any particular medical problems the care provider should be aware of  
such as seizures, cardiovascular problems, respiration, allergies, etc.? \_\_\_\_\_

\_\_\_\_\_

Physician's name \_\_\_\_\_ Phone \_\_\_\_\_

Hospital preference \_\_\_\_\_ Phone \_\_\_\_\_

Ambulance Service \_\_\_\_\_ Phone \_\_\_\_\_

Insurance information (company name, policy number, etc.) \_\_\_\_\_

\_\_\_\_\_

#### MEDICATION INFORMATION

Is the client receiving any type of medication?    ☐ Yes    ☐ No

If yes, please specify below:

Type/name of medication/dosage/how often & when/instructions

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

Please specify the purpose of each of the medications listed above (e.g., seizure  
control, respiratory infection, etc.) \_\_\_\_\_

\_\_\_\_\_

Where are these medications kept? \_\_\_\_\_

\_\_\_\_\_

### EMERGENCY CONTACTS

Circumstances in which parents wish to be contacted (e.g., client begins to run a fever) \_\_\_\_\_  
\_\_\_\_\_

If parents cannot be contacted, list of contacts in order of preference:

Name	Phone	Address
_____	_____	_____
_____	_____	_____
_____	_____	_____

Emergency phone numbers: police \_\_\_\_\_ Fire department \_\_\_\_\_  
Poison control center \_\_\_\_\_ Other \_\_\_\_\_

### HOUSEHOLD PROCEDURES AND INFORMATION

If there is no phone at the house, what is the location of the nearest pay phone or neighbor's phone which can be used in an emergency situation? \_\_\_\_\_  
\_\_\_\_\_

Emergency phone numbers:

Plumber \_\_\_\_\_

Electrician \_\_\_\_\_

Utility companies \_\_\_\_\_  
\_\_\_\_\_

Location of first aid kit in the home \_\_\_\_\_

Location of fuse box and spare fuses \_\_\_\_\_  
\_\_\_\_\_

Fire exit plan for the home \_\_\_\_\_  
\_\_\_\_\_

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Special emergency procedures (tornado, flooding, etc.) \_\_\_\_\_

Special instructions/restrictions on the operation of household appliance,  
cars, etc. \_\_\_\_\_

List of persons who are/are not permitted to visit the client in the parents/guardians'  
absence (please specify): \_\_\_\_\_

Other specific instructions, observations, or comments \_\_\_\_\_

Do you have any specific preferences for care provider characteristics and/or  
skills? \_\_\_\_\_

# GENERAL RELEASE FORM

I, \_\_\_\_\_, agree to the release  
(name of parent or guardian)  
and/or gathering of necessary medical, psychological, and other information and  
records on \_\_\_\_\_ which may be necessary  
(client's name)  
for the provision of respite care services. I also release the respite care program, its  
providers and administrators from all liability in the provision of such services. By  
my signature, I also grant permission for necessary and required transportation and  
medical care. In addition, I will not hold the respite care program, its providers and  
administrators liable for any accidental breakage of, in, or on my property and/or  
incident which might be construed as adversely affecting the health, safety, or wel-  
fare of others in or on the property during the provision of respite care services. I  
also acknowledge that I have read and understood this release agreement, that I  
have answered all questions to the best of my ability, and have provided full and  
complete information to the respite care program, coordinator, and/or care pro-  
vider.

\_\_\_\_\_  
(signature of parent or guardian)

\_\_\_\_\_  
(date)

## AUTHORIZATION TO ADMINISTER MEDICATION

I, \_\_\_\_\_, authorize \_\_\_\_\_  
(name of parent or guardian) (care provider's name)

to administer to \_\_\_\_\_ the following medications  
(client's name)

as instructed below:

	MEDICATION	DOSAGE	FREQUENCY/TIMES
1.	_____	_____	_____
2.	_____	_____	_____
3.	_____	_____	_____
4.	_____	_____	_____
5.	_____	_____	_____

This authorization extends from \_\_\_\_\_  
(date/time)

to \_\_\_\_\_  
(date/time)

Signed: \_\_\_\_\_  
(signature of parent or guardian)

Date: \_\_\_\_\_

CLIENT/CONSUMER FAMILY  
RESPITE CARE EVALUATION FORM

Family name \_\_\_\_\_ Client's name \_\_\_\_\_

Care provider's name \_\_\_\_\_ Date(s) of Service \_\_\_\_\_

How would you rate the service provided (please circle a number with 1 being unsatisfactory and 5 being totally satisfactory)?

1            2            3            4            5

Was the care provider on time?    ☐ yes    ☐ no

Did the provider spend time with \_\_\_\_\_ prior to your leaving?  
client's name  
☐ yes    ☐ no

Were you satisfied with the information which the care provider obtained from you about your family member?    ☐ yes    ☐ no

Please explain \_\_\_\_\_  
\_\_\_\_\_

Would you use this care provider again?    ☐ yes    ☐ no

Please explain \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

Please give your overall impression of the respite care services provided to your family member including both the positive aspects and any suggestions for improvement you might have: \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

How much did you pay the care provider? \$ \_\_\_\_\_

Family member's signature \_\_\_\_\_

### CARE PROVIDER EVALUATION FORM

Care provider's name \_\_\_\_\_

Family name \_\_\_\_\_ Client's Name \_\_\_\_\_

Date(s) of service \_\_\_\_\_ Hours of service \_\_\_\_\_

How would you rate the respite care period you spent with this client (please circle a number with 1 being unsatisfactory and 5 being totally satisfactory)?

1            2            3            4            5

Would you provide respite care service to this family again?

\_\_\_\_yes    \_\_\_\_no

Explain \_\_\_\_\_

\_\_\_\_\_

Were you satisfied with the information obtained from the family prior to the provision of service?    \_\_\_\_yes    \_\_\_\_no

Explain \_\_\_\_\_

\_\_\_\_\_

Did anything occur during the respite for which your training or parent information did not prepare you?    \_\_\_\_yes    \_\_\_\_no

If yes, please explain: \_\_\_\_\_

\_\_\_\_\_

Did the family leave a reference check list for you to consult in case of an emergency?    \_\_\_\_yes    \_\_\_\_no.

Please list any specific information about the client/family which might prove helpful or beneficial to someone providing respite care for them in the future: \_\_\_\_\_

\_\_\_\_\_

Amount paid for respite services \$ \_\_\_\_\_

Care provider's signature \_\_\_\_\_

### CARE PROVIDER INFORMATION

Name \_\_\_\_\_

Address \_\_\_\_\_ Phone \_\_\_\_\_

Height \_\_\_\_\_ Weight \_\_\_\_\_ Age \_\_\_\_\_

Please list additional contact phone numbers:

Business \_\_\_\_\_ Other \_\_\_\_\_

Please check the days when you will be available to provide respite care and list the times when you will be available:

Sunday \_\_\_\_\_ Times: \_\_\_\_\_

Monday \_\_\_\_\_ Times: \_\_\_\_\_

Tuesday \_\_\_\_\_ Times: \_\_\_\_\_

Wednesday \_\_\_\_\_ Times: \_\_\_\_\_

Thursday \_\_\_\_\_ Times: \_\_\_\_\_

Friday \_\_\_\_\_ Times: \_\_\_\_\_

Saturday \_\_\_\_\_ Times: \_\_\_\_\_

How much notice would you need before the respite period? \_\_\_\_\_

Will you be available for overnight or extended respite periods

\_\_\_\_Yes \_\_\_\_No

Do you have a car or other available transportation? \_\_\_\_yes \_\_\_\_no

Please list any preferences or limitations about service provision (include the types of disabilities you prefer to work with and those you would feel uncomfortable with, whether you would prefer to work with male or female clients, any limitations on travel, etc.): \_\_\_\_\_

\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

## **Record Keeping and Filing Systems**

Records and files which are kept in an orderly, logical fashion will prove most helpful to both you and the overall organization of the program. All consumer family and care provider information should be readily accessible, and procedures for maintaining that information should be consistent. If you have clerical help, or if records and files are to be included with those of your agency, you should be sure that everyone involved is familiar with the procedures and systems which are established. The following suggestions are offered as simplified ways of accurate, accessible record keeping.

As coordinator of the program, you should maintain at least three separate sets of files for your use:

### **1. A PERMANENT FILE FOR EACH CONSUMER FAMILY**

This file, kept in your office at all times, should be a master control file for all respite care services requested by and provided to that particular consumer family. This file will contain the original copies of the Respite Care Registration Form, all release forms signed by the family for each respite period, and the evaluation forms completed by both consumer family and care provider after each respite period. You should also keep a log on each respite period, cost/sliding scale information, and any personal notes you have made on that family. This should be a highly confidential file for your use in providing the highest quality respite care services possible for that family.

### **2. A PERMANENT FILE FOR EACH CARE PROVIDER**

This file, also kept in your office for your use, will contain three basic types of information on each care provider:

Personal data (employment application, reference information, W-2 and W-4 forms, time sheets, and payroll information)

The Respite Care Provider Information form (see page 2.65) which lists the days and times the provider is available for service, contact phone numbers, types of disabilities the provider prefers to work with and those with which he/she feels uncomfortable, etc.

Observational and evaluation information: your own notes about the care provider's interpersonal skills, communication skills, reliability, etc. You will gather this type of information during the initial employment interview, during the training sessions, and after actual respite care provision. You will also include all evaluation forms filled out by the consumer families.

### **3. A CONSUMER FAMILY/CARE PROVIDER UTILIZATION FILE**

This file will be given to the care provider prior to the provision of service to a particular family and will be returned to you after the respite care period. Much of the information in this file will be copies of data from the Consumer Family file which is kept in your office. Included will be a copy of the Respite Care Registration form, copies of all release forms for the upcoming respite period, evaluation forms from previous care providers, and any special information or observations made by you or previous care providers about the family or client. This might include any notations about special instructions given by the family, activities which proved helpful with the client or problems which arose during previous respite periods. While this file will be kept in your office, it is designed to be given to the provider when he/she has been matched with that particular family. The first time a provider serves that family, this information should be given well in advance and should be reviewed with the provider in order to point out any areas of concern, special needs, or additional information requirements.

You will notice that there is a great deal of duplicate information to be placed in each of these files; for this reason you will want to decide on some method of reproducing the forms. You may simply want to use carbon copies when the consumer families and care providers fill out the original copies of each form. Or, you may have access to a copy machine for duplication. Whatever method you choose, keep in mind that you will need three (3) copies of the Respite Care Registration form, two (2) copies of all release forms, three (3) copies of the evaluation forms, and one (1) copy of the Care Provider Information form.

### **Overall Program Control**

In addition to the consumer family files and the care provider files, you will need some method of organizing and maintaining overall program information (how many respites are being provided, to whom, when, and by which providers). If, for example, you receive a request for a particular provider on a particular date and time, you will need some method of responding to that request. You should know immediately whether that provider is available on the requested date and/or at the requested time.

A master calendar or bulletin board is one of the easiest and most accessible methods of program organization, and they are available in a variety of models and layouts (some for the wall and others for the desk). You may want to get a laminated calendar (which is erasable when written on with a felt-tip pen or marker) and fill in the dates of the respite period and the names of the providers as they are requested. You may even want to color code the various types of respite services: black for evening respite, blue for overnight, red for a weekend, etc. This calendar method will also help you plan for periods when the demand for respite care services is high (weekends, special holidays like New Year's Eve, the summer months, etc.).



If using all of the care providers is a concern, you might also consider some type of rotation system where a person is placed at the bottom of the list after he/she has provided respite care service. If you are serving a large metropolitan or geographical area, you may also need a pin map of your area to indicate each respite provision that has been scheduled.

The methods you use to organize your services will, of course, be up to you and will depend on the demands on the program, but some method which allows easy identification of service availability is highly recommended.

## IN-HOME RESPITE CARE PROGRAM DEVELOPMENT

### Section 9

#### Follow-up

The provision of respite care is not complete until a thorough follow up has been conducted. While there are forms to be filled out by both consumer and provider which evaluate the service provision, a follow up should also include a personal contact by the coordinator and a review of all information.

## *Section 9*

### **FOLLOW-UP**

This section will serve as a guide to help you obtain information from the care provider, client, and consumer family after respite service has been provided.

1. Have the care provider complete a service delivery evaluation check list (p. 2.63 this Unit).
2. Develop an open communication with the care providers and encourage them to contact you any time there is a question, problem, or need.
3. Request client/consumer family to complete a respite evaluation form (p. 2.61 this Unit).
4. Follow up respite care service with a telephone call to the family to determine whether service was satisfactory. Encourage the family to be as honest and open with you as possible.

The following are suggestions to assist you in the review of information you have received:

1. Review provider and consumer check lists within two days after completion.
2. Follow up review with a telephone call or personal interview to be sure that the provider handled all situations as appropriately as possible.
3. Contact provider and/or family if either check list indicates a particular need for personal attention.

## REFERENCES

Sullivan, R. C. "The Burn-out syndrome." *Journal of autism and disorders*, 1979, 9, 112-117.

## **IN-HOME RESPITE CARE PROGRAM DEVELOPMENT**

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## IN-HOME RESPITE CARE PROGRAM DEVELOPMENT

### *Section 1*

### **An Introduction to Training**

Introductory Notes to the Training Unit

General Guidelines and Suggestions

Handouts

Specific Information and Exercises

While the curriculum for your training sessions should be organized to meet the needs, format, emphasis, and time frames of your individual program, the suggestions included in this unit are designed to give you a variety of possible curriculum activities from which to choose. Included are general information, handout sheets to be duplicated and given to the trainees, role-play exercises, and specific instructions on how best to use the materials in this unit.

## Section 1

### AN INTRODUCTION TO TRAINING

#### Introductory Notes to the Training Unit

The information and materials in this training unit are designed to help you, as program coordinator and trainer, establish a curriculum for the training of respite care providers. The suggestions in this unit are based on observations of successful respite programs throughout the United States and the materials which have been used in these programs. Surveys were also conducted with potential consumer families (those who expressed an interest in respite care services), and the needs expressed by these families have also been incorporated into the program suggestions.

Because the training of care providers is as variable and individual as respite care programs themselves, the materials presented in this unit are flexible enough to be incorporated into a variety of program agendas and formats. As coordinator of the program, you will be formulating your own agenda for training, and these materials are intended to assist you in that process.

You will find three basic types of material in this unit, all of which are necessary for a complete, effective training program:

1. **GENERAL GUIDELINES AND SUGGESTIONS.** This type of material consists primarily of checklists which specify things to do (before, during, and after each training session) and hints which should be helpful in formulating an agenda, presenting the material during the training, and evaluating the effectiveness of the information. Many of these suggestions are only "common sense," but they are included for the coordinator who may not be familiar or comfortable with programs of this nature.
2. **HANDOUTS.** These materials can be duplicated and distributed to the trainees. In some instances, the materials are to be used in conjunction with a

particular training exercise; others are designed to accompany general information that is given during training. Specific instructions accompany these handouts whenever necessary, and the materials are marked "(HANDOUT)" at the bottom of the page.

3. **SPECIFIC INFORMATION AND EXERCISES.** These materials are designed to be directly incorporated into the program, and they follow this format:

**PURPOSE:** Why the information/exercise is included in the program and what you hope to accomplish during that particular session of the training.

**METHODS:** How that particular material/exercise can best be used in the training. This information includes role playing, presentations by you and/or guest speakers, group discussions, etc.

**MATERIALS:** What materials will be needed for the exercise. This may include handouts from the manual, pencils and paper which you will supply, overhead projector, movie projector, etc.

**TIME:** An approximation of how long the presentation and/or exercise should take.

**Notes to the Coordinator:** Special instructions or suggestions for that particular program segment or exercise.

One key point should be made here. You *MUST* be completely familiar with all of the materials in this unit before you can decide which can and cannot be used in your training program. A thorough reading and rereading of this entire unit will be helpful in making your training program as beneficial as possible. If you appear disorganized or unsure of yourself, your uncertainty will be reflected in the program. Remember, too, that the materials contained in this section are offered only as suggestions for your program. As with all other aspects of the respite care program, you must assess these materials and decide what will work for you and which segments of the training can readily be incorporated into the agenda for your training.



## IN-HOME RESPITE CARE PROGRAM DEVELOPMENT

### *Section 2*

#### **Training Program Goals**

Notes to the Coordinator

Training Competent Care Providers

Enhancing Communication

Achieving a Balance of Information

Training Glossary

The task of formulating a training program agenda may seem complicated and confusing. But this process can be simplified if you keep three basic program goals in mind at all times: (1) You want to train competent care providers; (2) You want to help trainees develop communications skills which will be useful in obtaining important information from families and clients; (3) You want to maintain a balance between technical information and information which must be obtained about an individual client. At all times you must stress that providers will be working with individuals, not handicaps, and while some knowledge about the handicapping condition will be beneficial, the most vital information will come from the family or the client. All of the materials in this unit are geared directly toward helping you attain these three vital program goals.

## Section 2

### TRAINING PROGRAM GOALS

#### Notes to the Coordinator

You may be faced with a variety of questions and potential problems when you begin to formulate the program you will be using to train care providers: How long should the program last? What is the most important information that trainees/care providers should receive? How much specialized, occupational information is necessary? Whom else could I/should I involve in the training? While such questions *may* seem complex and somewhat overwhelming, they can easily be simplified if you keep three basic training program goals in mind when you are developing your training agenda:

#### 1. Training Competent Care Providers

The program should be designed to produce competent, confident care providers. As program coordinator, you must be able to observe the trainees well enough and closely enough to determine their individual skills and abilities. Keep in mind that the ultimate decision as to whether a trainee will be a competent care provider rests with you, and your training program must be designed to help you make that decision.

#### 2. Enhancing Communication With Consumers and Consumer Families

The most pertinent, valuable information that the provider will need when he/she is working with a particular family will come from that family, so the major emphasis of the training should be directed toward helping the trainee/care provider elicit specific information from the client and consumer family. You must emphasize over and over again during the training that all of the forms and file information are to be used only as points of reference. The provider must get exact instructions and demonstrations from the client and consumer family, and the information presented in this unit will help in obtaining that information.

### **3. Achieving A Balance of Information**

The emphasis of the program should be the development of the trainee's/care provider's ability to get information from the client and consumer family, but the program must also provide some basic, specialized information such as first aid, CPR, an overview of developmental disabilities, etc. An over-emphasis of this type of information, however, can inundate the trainee and produce unnecessary feelings of inadequacy. Remember that you want the trainee/care provider to be prepared, not intimidated, so you must strive to maintain the right balance between the two types of information contained in the training program.

If you keep these three goals in mind at all times, you will find that the formulation of the agenda for your training program will not be quite as complicated as it first may seem.

#### **Training Glossary**

On the following page is a list of terms which are frequently used in the training sessions. They should be clearly understood by everyone involved in the program, and the use of these specific terms and their definitions should be as uniform as possible. At the beginning of the training program, you may wish to duplicate this list and give a copy to each trainee and any guest speakers.

## **Training Glossary**

### *BEHAVIOR MANAGEMENT*

The systematic application of specific contingencies on observable behavior. As applied to respite care, it is intended to help the care provider manage a situation in which a client is displaying some destructive or disturbing behavior.

### *CARE PROVIDER*

The person who will be providing respite care services to the consumer family. He/she acts as a parent substitute to the handicapped individual while members of the family are away from the home.

### *CLIENT*

The handicapped/developmentally disabled member of the consumer family. The client is the individual for whom respite care services are provided.

### *CONSUMER FAMILY*

The family with a developmentally disabled/handicapped family member who will be using respite care services. The consumer family (parents, guardians, relatives) will be away from the home during the respite care period.

### *DEVELOPMENTAL DISABILITY*

As defined by PL 95-602, any physical or mental handicap that began before the age of 22 which causes severe functional limitations. Generally the term refers to mental retardation, cerebral palsy, epilepsy, and autism, but it may also include muscular dystrophy, spina bifida, blindness, deafness, and mental illness provided the impairment occurred before the age of 22 and causes severe functional limitations.

### *RESPIRE CARE*

Temporary care provided to families with a developmentally disabled/handicapped family member. In-home respite is relief provided in the home of the consumer family; out-of-home respite is relief provided in surroundings other than the home of the consumer family/client.

(HANDOUT)

## IN-HOME RESPITE CARE PROGRAM DEVELOPMENT

### *Section 3*

### **Planning the Training Sessions**

Notes to the Coordinator

Suggested Training Agenda

Program Planning Considerations

Training Session Preparations

With the three goals from Section 2 in mind, you can now begin to plan the actual training sessions. As with so many other aspects of the respite care program, a number of variable factors must be taken into consideration, but some general ideas and suggestions are combined with specific recommendations and materials to help you in your planning.

### *Section 3*

## **PLANNING THE TRAINING SESSIONS**

### **Notes to the Coordinator**

The following agenda items are suggested on the basis of (1) a sampling of items included in the training programs of various respite care programs throughout the United States and (2) a survey of the concerns expressed by potential consumer families (Terraciano & Parham, 1980).

When planning the training program, consider each of these items very carefully and decide which can readily be incorporated into your program. (For example, will you be able to get a guest speaker for the overview of developmental disabilities? Is there a film available for you to use in establishing the ability vs. disability theme? Can you get a panel to discuss the need for respite care?) Considerations such as these must be made before any agenda planning can be formulated. You must then decide on the exact order of presentation. (How many days of training will be offered? How will the training be scheduled—how many hours per night or how many different days? When will speakers and/or panel members be available?) These and other similar questions must be answered before you can plan the training agenda.

The items listed in the suggested training agenda are ordered in a way that should prove logical and effective for any training program. (Note that the three interviewing exercises should be placed at the beginning, middle, and end of the program so that trainees will benefit from the basic purpose of each and from the experience they acquire throughout the course of the training.) Other agenda items should be scheduled around these interviewing exercises.

### **Suggested Training Agenda**

The following agenda items are listed in the order which should prove both logical and effective in achieving the goals of the training program. You may have to make some changes depending on the availability of speakers, films, equipment, etc.

1. Coordinator's introductory and welcoming remarks: An overview of the respite care program and the training sessions
2. Speaker or film to introduce the theme of the positive aspects of persons who are handicapped: Ability vs. Disability
3. Interviewing Exercise I
4. CPR Training
5. An Overview of Developmental Disabilities (basic information and reiteration of the ability vs. disability theme)
6. Interviewing Exercise II
7. First Aid Training
8. Seizure and Medication Training
9. Behavior Management Discussion and Exercise
10. Interviewing Exercise III
11. Administrative Information: Forms, procedures, etc.
12. Competency Assessment Exercise

#### **Program Planning Considerations**

The organization and success of the training program are your responsibilities, and the trainees will be looking to you for direction and guidance during the course of the training sessions. Preplanning is the key to a successful program, and the following suggestions are offered to help with your preplanning.

1. *When and where will you be conducting the training?* You must first decide on how the training will be divided. Should the program be broken into blocks of two or three days/evenings? How many hours per day or evening should be used for each session? Who are your trainees, and when will they be able to attend training sessions? Where will the actual training take place? Does your agency have an available facility? If so, will it accommodate all of the trainees? If not, what other arrangements will have to be made? (Note: Your advisory board can be very helpful in obtaining a place for the training.)
2. *What agenda will you be using?* Many of your agenda considerations will depend on the answers to questions in number one above, but an overview of the program will help you to determine a tentative agenda from which to work.
3. *How many trainees will you accept for each training program?* These materials have been designed to include small group discussions. Groups of trainees which number more than fifteen will probably be excessively large and may hinder the success of the discussions and the freedom of trainees to participate actively. It is suggested that you limit your group to fifteen or twenty. If you have the need to train more, you will have to adjust your agenda to accommodate a large group, or you may have to plan for two separate training sessions.

4. *Who will be your speakers?* Potential speakers should be contacted well in advance of the program. They should be aware of exactly when they will be speaking, the amount of time you will want them to speak, the level of expertise of the trainees, etc. **YOU MUST MAKE CLEAR TO EACH SPEAKER THE INTENT OF THE TRAINING IN GENERAL AND THE SPECIFIC PURPOSE OF THE PRESENTATION HE/SHE WILL BE MAKING.** You do not want the presentation to be too technical for the trainees, nor do you want the information to be repetitive.
5. *What materials will be needed for the program?* You should establish well in advance of the training program what films, handouts, etc. you will be using during the training sessions. If some material needs to be ordered (the film, for example), this should be done in advance so that it will be available for the session you have planned. Copies of handouts should be made before the training begins.
6. *Will any special equipment be needed?* If movie projector, overhead projector, and other audio-visual equipment will be used, is it available through your agency? If not, arrangements should be made so that the equipment will be available when you need it. (Some rental agencies, for example, require a two-advance notice).

### **Training Session Preparation**

#### *ADVANCE PREPARATION*

1. Make sure that all trainees, speakers, and program participants are notified of the dates, times, and location(s) of the training sessions. This notification should be made well in advance to allow those involved to make arrangements for transportation, baby-sitters, etc.
2. If there are any changes in times, dates, locations, you must be responsible for notifying each program participant and trainee.
3. Check and double check the room and seating arrangements. Make sure you have enough chairs and that they are properly arranged before the sessions begin. See that the room temperature is comfortable and lighting is adequate.
4. If you will be providing coffee or other refreshments, make such preparations ahead of time (coffee pot, cups, sugar, cream, spoons).
5. Make whatever arrangements are necessary for any equipment you will be using: overhead or movie projectors, slide presentations, screen, tape players. Check the equipment to be sure it is working properly. Do not wait until the session begins to find out that you do not have an extension cord, light bulb, or electrical outlet.
6. Make a list of materials you will be using and make sure you bring these materials with you for each training session: pencils, paper, handouts, name tags.
7. Outline the topics you will be covering for each session. Remind guest speakers about the topics, times, limitations.



8. If you will be using films or slides, view them before the first session. Rental equipment and materials can be broken or damaged, and you will want to know this before the sessions begin.
9. When dividing the trainees into small groups for discussions or exercises, plan ahead for the best way to facilitate these arrangements. You may divide the whole group into smaller groups before the first session; you may want them to "count off" and have all the "ones" in the first group, all of the "twos" in another, and so on. Do not wait until the last minute to decide on a method or you will waste valuable time.
10. Have your breaks carefully planned and list them on the agenda. Tell the trainees that you will be taking a fifteen-minute break at nine o'clock. You don't want them wandering in and out of the room, and, following these breaks, you want to be able to begin each session on time.
11. Prepare handouts, overhead transparencies, and posters ahead of time.
12. When using the interviewing exercises, make sure that you have enough copies of the client/parent descriptions and exercise evaluation forms for each trainee.

#### *PREPARATION FOR EACH SESSION*

1. Arrive early to check the room (temperature and lighting) and seating arrangements. Don't rely on the fact that there *were* enough chairs *last time*. Other groups may have used the room, or tables/chairs may have been removed since your last training session.
2. Set up the audio/visual equipment and check it again. Start the coffee if you are serving refreshments. Take care of all these little details before the trainees arrive so that you will not have to waste valuable training session time.
3. **START ON TIME.**
4. Follow your agenda closely, and move from subject to subject as planned. This is particularly important if you will be using guest speakers, panel discussions, etc.
5. Don't allow discussions to go on too long. You have material and information that you want to cover, but don't overdo it. If the group discussions have covered all of the points that you feel are important, move on. The trainees will be looking for direction from you in this area.
6. Encourage the trainees as the program progresses. Remember that much of the information and many of the exercises will be new to them, and they will have some misgivings about their performance and abilities.

## IN-HOME RESPITE CARE PROGRAM DEVELOPMENT

### *Section 4*

### **Observational Guidelines**

One of your most important responsibilities as coordinator and trainer will be the evaluation of the trainees as potential care providers for the program. This assessment requires a combination of common sense, intuition, and a few observational keys to be used during the training sessions.

#### *Section 4*

### **OBSERVATIONAL GUIDELINES**

**PURPOSE:** To give the coordinator some areas of observation to be used in the assessment of provider trainees.

**METHOD:** Coordinator Observation.

**MATERIALS:** None.

**TIME:** Ongoing (throughout all training sessions).

#### **Notes to the Coordinator**

As program coordinator, you are going to be assessing and evaluating both consumer families/clients and care providers. You will probably not have the time to assess each potential care provider individually during the training session, but the following is a list of areas that you may wish to pay particular attention to when observing the trainees during the program.

##### **A. Personal Organization**

1. Punctuality for training sessions
2. Appropriate dress and personal appearance
3. Organization in his/her approach to the training task
4. Is/is not easily distracted from the task
5. Does not appear to be impulsive in his/her decision making

**B. Participation In Training Program**

1. Voluntarily participates in discussions, exercises
2. Accepts instructions as given
3. Completes task as assigned
4. Appears self-sufficient
5. Is innovative in his/her approach to training tasks

**C. Peer Relationships**

1. Exhibits a friendly, pleasant attitude during training sessions and refreshment breaks
2. Is sensitive to the needs/feelings of other trainees and offers as well as accepts constructive suggestions
3. Displays appropriate communication skills

These are simply guidelines, and you will undoubtedly have additional criteria for your observations. As mentioned in the "Notes to the Coordinator," you will not be able to assess each trainee completely on an individual basis. However, the more you know about your trainees, the easier it will be for you to make decisions about their capabilities and potential as providers. These observations will also assist you in matching care providers with consumer families for the provision of actual respite care services (see p. 2.41).

## **IN-HOME RESPITE CARE PROGRAM DEVELOPMENT**

### *Section 5*

### **The Training Sessions**

The First Training Session

Introduction to Developmental Disabilities

An Overview of Developmental Disabilities

Care Provider-Consumer Family Interview Exercise I

First Aid and CPR

Seizure Information

Medication Information and Exercise

Behavior Management

Care Provider-Consumer Family Interview Exercise II

Care Provider-Consumer Family Interview Exercise III

Administrative Information

Competency Assessment

The organization of training sessions requires careful planning and orchestration, and the information in this section offers suggestions on what should be included in a respite care training program as well as exercises and handout materials to be used in conjunction with your training.

## *Section 5*

### **THE TRAINING SESSIONS**

#### **Introduction To The First Training Session**

**PURPOSE:** To present a brief overview of the goals of the training program and what the trainees should expect during the program; to have trainees get acquainted with each other.

**METHOD:** Presentation by Coordinator  
Questions and Answers  
Get-Acquainted Exercise

**MATERIALS:** Agenda handout (listing dates, times, and locations of all upcoming training sessions)

**TIME:** 30-45 minutes

#### **Notes to the Coordinator**

You must gear your opening remarks to fit the program you have designed. Only you know just what will be included, what will be expected of the trainees, and what the agenda will include. You do not, however, want to over-explain the program at this point; let the program speak for itself as the sessions progress. Too much information or information that may sound too technical can make the trainees feel that too much will be expected of them.

Remember that the trainees will be somewhat nervous and anxious about what they will be doing and what will be expected of them. Reassurance and clearly-defined program goals will help them overcome these feelings of anxiety.

The following suggestions are offered as topics which you might want to address at the beginning of the program:

1. A brief explanation of just what respite care is. You will have already explained this to the trainees when you screened/interviewed them, but a brief introduction will be helpful in beginning the program.
2. A brief explanation of the overall goal of the respite care program, noting that the main objective is to assist the family in maintaining a normal, routine schedule with the family member who is handicapped functioning as an integral, harmonious member of that family.
3. A statement of the goals and objectives of the training program:
  - a. To stress the competencies and abilities of persons who are handicapped as opposed to what these persons cannot do (ability vs. disability)
  - b. To help the trainees develop skills to assist them in obtaining specific information from the consumer family and client.
  - c. To provide basic background ("technical") information on first aid, CPR, developmental disabilities, and handicapping conditions.
  - d. To familiarize providers with both the needs of persons who are handicapped and the most effective, efficient means of meeting those needs.
  - e. To assist the trainee in becoming a confident, competent care provider.

You will want to begin this first training session with a warm-up exercise to get the trainees acquainted with each other and to make them feel more comfortable with one another as they begin to work together. You may select one of the following activities, or you may use an exercise of your own:

1. If the group is small, and if you know something about each person, you can go around the room and introduce each member. Look for something interesting to tell about each trainee.
2. With the group seated in a semi-circle, take a piece of yarn about a yard long and have each person, beginning with you, tell the group why he/she is interested in becoming a care provider. Each person speaks only as long as it takes to wind the yarn around the index finger.
3. Ask each trainee to write an answer to one of the following:

One reason I am interested in this program is \_\_\_\_\_

Something I hope to accomplish while working in this program is \_\_\_\_\_

Then go around the room and have each trainee tell his/her name and then read what he/she has written. You may want to write (on large newsprint sheets or a blackboard) the person's name and one or two words summing up what each has said (i.e., Linda—help others; Bob—experience.)

No matter what type of warm-up exercise you choose, explain to the trainees that the training program is a cooperative effort and will require participation on the part of everyone involved. The warm-up exercise is simply one way of starting that cooperation by having the trainees get to know each other as soon as possible.

## **Introduction to Developmental Disabilities**

**PURPOSE:** To establish an emphasis on the positive aspects of a person with a handicap—stressing his/her abilities rather than disabilities.

**METHOD:** Presentation by a guest speaker, perhaps an individual who is handicapped who can point out the positive aspects of his/her life, or

A presentation by someone who works with people with developmental disabilities—someone who can illustrate the abilities and positive aspects of a person who is handicapped, or

A short film which emphasizes the positive theme you are seeking to stress at this point in the program. Check with your agency or other human service programs in the community for the availability of such a film.

**MATERIALS:** Will vary depending on which of the methods you choose.

**TIME:** 15-20 minutes

### **Notes to the Coordinator**

The general public is very poorly informed about individuals who are handicapped, and many of the trainees will bring their misinformation, misconceptions, and prejudices with them to the training sessions. While you will not have the time to re-educate them completely during the training, you do have the opportunity to combat many of the negative attitudes which have been developed by lack of accurate information and by an overall fear of the subject. The theme of abilities of the people with developmental disabilities must be established as early in the program as possible so that it can be restated and reinforced by the training exercises and experiences later in the training. You may also wish to follow up this introduction information with a brief group discussion to allow trainees to express their feelings and experiences.



## **An Overview of Developmental Disabilities**

**PURPOSE:** To give the trainees an understanding of the basic aspects of developmental disabilities, what handicapping conditions are included, and some general information about each condition.

To help the trainee recognize the positive aspects of the individual who is developmentally disabled—an emphasis on what he/she CAN do rather than what he/she is UNABLE to do.

**METHOD:** A presentation by one of the following or a combination of these possibilities:

- a professional from the field of developmental disabilities
- a panel discussion with persons who are developmentally disabled or families with a member who is developmentally disabled.
- a presentation by care providers who have been with the program and who have had experience with clients. (This, of course, will not be possible until the program has been operating for some time.)

**MATERIALS:** A handout on the major handicapping conditions (mental retardation, autism, epilepsy, cerebral palsy, blindness, hearing impairment) to be used as a glossary/reference. Guest speakers or panel discussion members may also have materials to hand out to the trainees.

**TIME:** 1-1½ hours

### **Notes to the Coordinator**

Many of the trainees will have little or no knowledge about the term "developmental disability." While you do not want to overwhelm them with technical, medical, or legal jargon that will be of very little practical help to them, you do want them to be familiar with the basic concepts of developmental disability and the particular handicapping conditions included in the definition. Most importantly, you want to emphasize the positive aspects of the client—what he/she is able to do, not what his/her limitations are. Remember that over 90% of persons who are developmentally disabled are only mildly or moderately disabled in some area of their development, and only a small percentage require *extensive* assistance. For example, Robinson & Robinson (1976) stated that of the 6.8 million people in the United States estimated to be mentally retarded (with an I.Q. of less than 70), only 105,000 could be classified as being profoundly mentally retarded. Similar estimates were noted by Doolittle (1976) who cited the Association for Retarded Citizens' estimate that 1.5% (85,000) of all mentally retarded persons in the U.S. are profoundly retarded, 3.5% (200,000) severely retarded, 6.0% (350,000) moderately retarded, and 89% (5 million) mildly retarded.

Since the major emphasis of the training program is the development of the trainees' abilities to obtain useful, practical information from the consumer family and the client, there is no reason for the trainee to know all of the technical definitions and

medical characteristics of each handicapping condition; however, you do want the trainees to have a basic knowledge—a general introduction or OVERVIEW. Keep in mind that specific information about the individual client (and that individuality must be stressed over and over again) will come from the individual and that person's family. **TRAINEES WILL BE DEALING WITH PEOPLE, NOT HANDICAPPING CONDITIONS ALONE.** The medical definition of an epileptic, for example, will give little detailed information about the individual client.

Explain to the trainees that some information about the various handicapping conditions can be found on the handouts, but the most important information will come from the client and the client's family.

### **Autism**

Autism is a syndrome characterized by severe disorders in communication, learning, and social relatedness. Research indicates it is caused by a disorder in the mechanism of the central nervous system which processes sensory stimuli. No known factors in the psychological environment of a child can cause autism.

National Society for Autistic Children  
1234 Massachusetts Avenue N.W.  
Washington, D.C. 20005

### **Blindness**

There are many definitions of severe visual impairment and of blindness, all referring to how well the individual can see even with the best corrective lenses. A person is said to be "legally blind," a measure used to determine eligibility for economic assistance and other programs, if the person's central visual acuity does not exceed 20/100 in the better eye with correcting lenses or the visual field is less than an angle of 20 degrees. In simpler terms, a person is considered legally blind if unable to see more at a distance of 20 feet than someone with normal sight can see at a distance of 200 feet. It is estimated that there are about 11.4 million persons in the United States with some kind of visual impairment, but the American Foundation for the Blind prefers that the term "blindness" be reserved for a complete loss of sight with all other degrees of visual loss considered as visual impairment.

American Foundation for the Blind, Inc.  
15 West 16th Street  
New York, New York 10011

### **Cerebral Palsy**

Cerebral palsy is a condition caused by damage to the brain, usually occurring before, during, or shortly following birth. "Cerebral" refers to the brain, and "palsy" to a disorder of movement or posture. It is neither progressive nor communicable. Neither is it "curable" in the accepted sense, although it is often amenable to training and therapies. Approximately 10,000 infants are born with cerebral palsy each year, and some 2,000 young children acquire the condition as a result of head injuries. Cerebral palsy is not a disease.

United Cerebral Palsy Associations, Inc.  
66 East 34th Street  
New York, New York 10016

(HANDOUT)

## **Epilepsy**

While there are many definitions of epilepsy, the word is generally applied to a number of disorders of the nervous system, centered in the brain, so it is more exact to say "the epilepsies." The term comes from the Greek work for "seizures," and seizures of one kind or another are the primary characteristics or symptoms of all forms of epilepsy. However, not all seizures are epileptic in nature. While the cause for epilepsy cannot always be pinpointed, scientists agree that epilepsy can result from defects in the brain, brain injury before, during, or after birth, head wounds, chemical imbalance, poor nutrition, childhood fevers, some infectious diseases, brain tumors, and some poisons. Approximately 2 million Americans have epilepsy.

Epilepsy Foundation of America  
4351 Garden City Drive  
Landover, Maryland

## **Hearing Impaired**

The hearing impaired comprise two distinct groups: the deaf and the hard of hearing. The critical factor in determining whether a person is hard of hearing or deaf is the person's means of speech reception. The hearing loss of deaf people is so severe that they receive communication almost entirely through their eyes. The hard of hearing are those who have losses ranging from very slight to very severe, and they depend mainly on their ears, with or without amplification, for communication.

Deafness R&T Center  
School of Education  
New York University

## **Mental Retardation**

The American Association of Mental Deficiency defines mental retardation as significantly subaverage general intellectual functioning existing concurrently with the deficits in adaptive behavior, and manifested during the developmental period.

Association for Retarded Citizens  
2501 Avenue J  
Arlington, Texas 76011

(HANDOUT)

### **Mild Mental Retardation**

Persons at this level can master basic academic skills, while adults at this level may maintain themselves independently or semi-independently in the community (Grossman, 1977).

### **Moderate Mental Retardation**

Persons at this level can learn self-help, communication, social and simple occupational skills, but only limited academic or vocational skills (Grossman, 1977).

### **Severe Mental Retardation**

Persons at this level require continual and close supervision, but may perform self-help and simple work tasks under supervision (Grossman, 1977).

### **Profound Mental Retardation**

Persons at this level require continual and lasting supervision but may be able to perform simple self-help tasks; profoundly retarded persons often have other handicapping conditions and require total life-support systems for maintenance (Grossman, 1977).

(HANDOUT)

## CARE PROVIDER-CONSUMER FAMILY INTERVIEWING EXERCISE I

**PURPOSE:** To introduce, through an experimental approach, some basic information-gathering techniques.

To involve the trainees actively in the training process through role playing, through the sharing of experiences and feedback, and through discussion in group sessions.

To sensitize the trainees to (a) the feeling of being interviewed and (b) the conducting of interviews with the families of handicapped individuals.

To introduce several crucial points early in the training:

1. Positive thinking—thinking in terms of the client's competencies rather than his/her disabilities.
2. Describing clients in terms of their individual personalities rather than using diagnostic labels and stereotypes.
3. Information gathering—the gathering of pertinent information from parents and relatives of the client.

**METHOD:** Small group exercises; small group discussion; group discussion.

**MATERIALS:** Pencils and paper; one copy of client description for each "parent" trainee; list of Important Aspects of Interviewing Exercise.\* Training rating form for each trainee.

\*Transparency may be used with overhead projector, a poster large enough for all to read, blackboard if available, or copies to be distributed to each trainee.

**TIME:** 1-1½ hours.

### Notes to the Coordinator

The following exercise is the first in a series of experiences that the respite care provider trainees will simulate during the training. Each of these exercises has been designed to use active learning procedures which include role playing, individual feedback, and group discussion.

The role playing component of this and other exercises in this training package has been included for several reasons: (1) active learning is generally considered to be a more effective manner of training new employees or teaching employees new skills; (2) research has confirmed that more "carry over" to the actual job occurs when preservice employees are actively, rather than passively involved in training; (3) role playing is used to enhance the sensitivity of the trainees to some of the feelings experienced by families who will be utilizing respite services; (4) role playing will enhance the recognition of possible anxieties that the trainee may have about interviewing families. These anxieties can be handled most effectively in the training sessions, before the trainee provides actual respite care services.

Respite care situations often produce anxiety for trainees, but such feelings can be alleviated if attention is focused on the exercise itself and not on the potential embarrassment or inexperience of the individuals involved. Pairs or small groups will assist the trainees in overcoming their reluctance to participate since constructive comments and criticism are much more readily given and accepted in a small group. Feedback from other trainees will help to develop a sense of support among the trainee group while, at the same time, presenting the important issues of the program itself.

The group discussion component (which follows the small group discussions in some of the interviewing exercises) is designed as a time for trainees to present their observations to you and to the entire group. At this time, you can stress points of importance and can call for examples and/or suggestions. The format of group discussions must be set by the trainer, but the trainees should be responsible for content and the actual discussion. Mutual sharing of experiences and feelings will provide the trainees with the most information and skills.

The first interview exercise is designed to be conducted during the initial stages of training. (Ideally this exercise should be conducted during the first evening or three-hour block of training.) In general, most of the trainees will have had little or no training in either developmental disabilities or interviewing techniques. Therefore, their initial performances should not be expected to be very professional.

Several reasons exist for the use of this exercise during the early stages of training: (1) the exercise will serve as a "baseline" on which the progress of the trainee can be informally monitored by the trainee as well as the trainer; (2) the exercise will help to establish an early sensitivity to the pressures and problems of being the parent of a handicapped person, thus adding relevance to the exercise and the program in general.

Trainees should be expected to feel uneasy and unsure about participation in this type of exercise. Such anxiety is natural and will be felt, to some degree, prior to the actual respite experience. By repeated simulation experiences, this level of anxiety will decrease as the trainee's level of competence improves, and the trainee will become much more comfortable in his/her role of "interviewer."

Set up the room in such a manner that several groups can work comfortably in separate areas without disturbing or distracting one another. If there is not enough room in your training area, alternate arrangements should be made (each group working in a small room or office). Leave room for the trainer to circulate from one group to another with a minimum of distraction.

### **Interviewing Exercise Procedures**

It is very important that the trainees fully understand the purpose and importance of this exercise (and the other interviewing exercises which come later in the training). While you will want to present this explanation in your own words, the following dialogue is offered as a sample of the type of information you will want to present to them and the manner in which that information might be presented.

COORDINATOR: In this segment of your training, we are going to give you some practical interviewing experience that will be valuable to you as a respite care provider. No one will be able to tell you more about the person you will be caring for than that person's parents, guardians, relatives, and family. In order to benefit from the wealth of experience and knowledge that these people possess, you must develop some basic interviewing techniques and skills which go far beyond the simple asking questions found on a form or questionnaire. Good interviewing involves establishing a relationship with the person with whom you are speaking. It also involves asking questions and soliciting information from the client you will be working with.

In this exercise, you will be divided into groups of two (or more in some cases) with one person playing the role of the parent and the other playing the role of care provider. You will also switch roles so that each of you will have the opportunity to experience both roles.

You should now divide the trainees into small groups. The size of these groups will, of course, depend on the number of trainees in the program, but ideally there should only be two in each grouping. Give each group a client description sheet handout.

COORDINATOR: For the next ten minutes, the person playing the role of the care provider will conduct an interview with the "parent." Those of you who are playing the role of care provider will try to elicit information which you feel will be helpful in working with the client. Remember that this is only a ten-minute exercise, and you should not try to establish a life history of the client. Stick to what you think will be the most important information you will need to know about that individual, and remember that you are dealing with a person, not a set of statistics or data.

It is very natural to feel nervous about role playing, and most of you have had no previous experience in this type of exercise. No one is expected to do a perfect job on this exercise, and you will have several other opportunities to learn more about interviewing skills, techniques, and methods later in the training.

At the conclusion of this exercise, we will meet as a group to discuss your experiences, and I will give you some suggestions as to how you might improve your performance. When we discuss our experiences, we will see how many different approaches have been utilized and how many different



points were addressed in each group. One of the best things about an exercise such as this one is that there are few things you can do which might be considered "wrong."

Those of you who are playing the role of the parent should feel free to make up any information that is not on the client description sheet if the questions you are asked go beyond the scope of that description. Should a problem arise, just raise your hand and I will try to help you.

Those of you playing the role of the parent should make note of the following during the interview: What topics were you questioned about which were covered by the description sheet? What topics were not covered by the sheet? What basic types of questions were you asked? What information were you not asked about which you feel might have been helpful?

Information of this type will be helpful in the group discussion and will also be helpful when we design additional client descriptions to be used in future training programs.

Good luck and have fun. Remember that no one is expecting you to be perfect the first time.

You should now allow each group to conduct an interview for about ten minutes. When these interviews are over, you might add:

Now I would like for you to discuss your feelings with your partner. How did it feel to have someone ask you questions? What type of questions were asked? Do you have any helpful suggestions? Were you comfortable or uncomfortable during the exercise? Why?

At the conclusion of these brief discussions (5-10 minutes), pass out another client description sheet and have the trainees reverse roles. Be sure that each group gets a different client description handout for the second part of this interviewing exercise, although it is okay for several different groups to use the same handout. Just be sure that those who are partnered together have two separate cases to discuss. Sample client description sheets are found on pages 3.36 to 3.39. You may want to duplicate and use them, or you may want to compose others that are more appropriate to the specific nature of the program and the clients the program will be serving.

At the conclusion of the second ten-minute interview and brief-discussion session, give the trainees a fifteen-minute break, in the same room if possible, to allow for some informal discussion about the interviewing exercise. At the conclusion of the break, arrange the trainees in a semi-circle to help stimulate better interaction and discussion.

At this point you will want to display or distribute "Important Aspects of Interviewing Exercise I" (p. 3.40), and direct the trainees' attention to Item 1, "Establishing Rapport." After you give a brief (1-2 minutes) description of this concept, turn the discussion over to the trainees and ask how one might establish a rapport and encourage them to give examples from their experiences during the interviewing exercise. Continue to discuss the seven points in the same manner. At the conclusion, ask the trainees for their suggestions of other items that might be included on the list.

During this entire exercise, it is important that you encourage the trainees; remind them that this is only the first of several similar exercises and that everyone will improve his/her skills as the training progresses. Do not allow the trainees to become discouraged about their inabilities or mistakes.

At the conclusion of the group discussion, pass out a training rating form (p. 3.40), to each trainee and ask each person to fill it out. You will use these forms to evaluate the effectiveness of the exercise and to give information that might be helpful in making any modifications for future training programs.

### CLIENT DESCRIPTION I

Points to be gathered in the interview:

Name: Karen

Age: 23

Preferred Activities: Karen enjoys playing records and dancing. She also enjoys working with clay and has made some bowls, cups and ashtrays.

Daily activities: Karen works at the local sheltered workshop for the blind as a receptionist at the front desk.

Medical problems: No special medical precautions.

Physical problems: Karen has little use of her legs, and she moves about in a wheelchair. She also has limited vision which does not permit her to read from regular books (she can read Braille) and watches TV (she likes to listen). Karen is able to navigate the house as long as objects are not moved out of place.

Household skills: Karen loves to cook, but needs some help in measuring ingredients, getting articles on high shelves, and distinguishing between the contents in various cans and boxes. Karen is fully capable of feeding, dressing, and bathing herself.

Karen is somewhat shy and takes some time to become friendly with strangers. Usually, if she spends some time with a stranger while a family member or friend is present, she "warms up" to her new acquaintance after about a half hour. Karen becomes angry when people refer to her as crippled or disabled. She is quite intelligent and plans to go to college to become a teacher.

(HANDOUT)

## CLIENT DESCRIPTION 2

Points to be gathered in the interview:

Name: Jason

Age: 4 years

**Preferred Activities:** Jason prefers to spend most of his time playing on the floor with toy trucks, cars and his wagon. He will watch cartoons on TV for only 5 or 10 minutes at a time as he loses interest in TV very quickly. He also enjoys playing with water, and if not supervised, will put his hands in the toilet bowl or turn on the bathtub and watch with delight as it overflows.

**Daily Activities:** Jason attends a special education preschool in the community every morning. He also receives speech therapy twice a week.

**Medical Problems:** Jason receives medication twice a day (8 am and 8 pm) in liquid form. It must be mixed in Kool Aid or he will not take it.

**Physical Problems:** Jason travels about the house with little difficulty. His vision and hearing appear to be normal.

**Household Skills:** Jason feeds himself with his hands. When eating soup or other spoon or fork foods, he is usually fed by his parents. He sometimes will throw food off his plate if not carefully supervised. If all else fails, he will eat peanut butter sandwiches. He can put on pull-over clothes without help, but needs help with buttons, zippers, and shoe laces.

Jason enjoys the company of others. Although he does not talk to the person he is with, he likes someone nearby. When left alone, he tends to get into trouble. His speech consists of nursery rhymes and songs. As yet, he shows no verbal communication with the exception of these rhymes.

(HANDOUT)

### CLIENT DESCRIPTION 3

Points to be gathered in the interview:

Name: Lisa

Age: 7 years

Preferred Activities: Lisa loves to read and write. She will spend hours in her room reading books or writing in her notebook. She doesn't like playing with other children because they often make fun of her inability to hear and her use of sign language.

Daily Activities: Lisa attends a local elementary school and is in a normal second-grade class. Her teacher talks slowly so that Lisa can read her lips and is also able to communicate with Lisa in sign language and through written notes.

Medical problems: None.

Physical problems: Lisa has been unable to hear since birth. Although she has learned to speak, her speech is very difficult to understand and she prefers to communicate through sign language and, if necessary, through notes.

Household Skills: Lisa loves to help her mother with household chores. She is very neat and helps bathe and dress her baby brother. She needs no help dressing, feeding or bathing herself.

Lisa is very sensitive to the teasing she receives from her peers. She often returns from school crying because of the treatment she receives from the other children at school. She is extremely attached to her mother and does not like to be left alone with strangers. For this reason, Lisa's parents have been hesitant to leave her with a baby-sitter. She enjoys teaching sign language to others and this is usually a good way to "break the ice" with her.

(HANDOUT)

#### **CLIENT DESCRIPTION 4**

Points to be gathered in the interview:

Name: Bobby

Age: 12 years

**Preferred Activities:** Bobby enjoys bowling, swimming and other outdoor sports. He also enjoys watching baseball and football games on TV, and his room is decorated with pictures of his favorite athletes. He also enjoys working with his hands on model planes and arts and crafts projects.

**Daily Activities:** Bobby attends a special education school in his community. Although he is 12 years old, his school work is that of a much younger child. He is in speech therapy classes at his school to help improve the clarity of his speech.

**Medical Problems:** Bobby has a history of frequent colds and virus infections. He is susceptible to this type of problem. He also is allergic to penicillin and some other medications.

**Physical Problems:** None.

**Household Skills:** Bobby is capable of dressing and bathing himself (needs to be told to get out of the shower as he will stay in for an hour if not told to get out). Although he can feed himself, he tends to eat too fast if not reminded to "slow down."

Bobby is loud and active and fun to be with. He makes friends very quickly and is always eager to talk about or play baseball or football. At times Bobby is difficult to understand, especially when excited, and he must be asked to repeat himself at times.

(HANDOUT)

## IMPORTANT ASPECTS OF INTERVIEW EXERCISE I

1. Make the parent feel comfortable by establishing rapport.
2. Find out the nature of the client's handicap. Use of descriptions and examples are more useful to you than diagnostic/medical terminology.
3. Stress the client's competencies. What can he/she do, not what he/she cannot do.
4. Parents' suggestions of how you might "break the ice" with the client.
5. Find out what the client likes to do.
6. Don't rely on professional jargon. Speak in the same terminology as the parents. Ask questions about terms you might not understand.
7. Are there any special precautions that you should know about?

(HANDOUT)

### TRAINING RATING FORM

TRAINING TOPIC: Care provider-Consumer Family Interviewing Exercise I.  
I would rate this training exercise as follows:

BORING						INTERESTING
1	2	3	4	5	6	7
CHAOTIC				ORDERLY		
1	2	3	4	5	6	7
USELESS				USEFUL		
1	2	3	4	5	6	7
POOR LEARNING EXPERIENCE				GOOD LEARNING EXPERIENCE		
1	2	3	4	5	6	7
ANXIETY PRODUCING				NON-ANXIETY PRODUCING		
1	2	3	4	5	6	7

Comments about this training exercise: \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

(HANDOUT)

## FIRST AID AND CPR TRAINING

**PURPOSE:** To assist the care providers in gaining confidence in dealing with an emergency situation which might occur during the course of the respite care period.

**METHOD, MATERIALS, TIME:** Will depend on the option chosen for the program; see "Notes to the Coordinator" below.

### Notes to the Coordinator

Ninety-three percent of the surveyed respite care programs throughout the United States included some type of first-aid instruction in their training programs. In addition, a Needs Survey of Parents of Developmentally Disabled Persons in Lubbock, Texas, (Terraciano & Parham, 1980) indicated that parents felt the most important areas of training were those in the medical areas—first aid, CPR, seizure information, and the administration of medication. While such concerns on the part of parents are understandable, you must emphasize to both consumer families and care provider trainees that *emergency situations—those which would require the use of first aid or CPR—will be the exception and not the rule in the course of respite care provision*. You do not want to "oversell" this facet of the training. Basic knowledge, common sense, and the stability of care providers will be three general characteristics which will be most important if such a situation should arise, and these are three characteristics you will be looking for in trainees during the training sessions. As you guide the trainees through the program, you will, through very careful observations, become aware of their potential proficiency in handling emergency situations. In addition, the interviewing techniques for obtaining information from consumers will be of vital importance in this area. These combined elements will make providers capable of dealing with any situation which might occur, including an emergency situation.

But, some type of first aid and CPR training should be included in the training program, and the level and depth of that training is a decision that you will have to make when you are planning the training program. A number of options are available to you:

1. Your agency may be governed by state or federal regulations which mandate the type and extent of training which providers/employees must be given. To fulfill such requirements, ongoing training may be offered by the agency, so find out about these regulations and the training offered and/or required.
2. Local Red Cross chapters and/or hospitals in the community usually offer extensive CPR and first aid courses at no charge, so you may wish to check with them for details. Initial certification in CPR usually requires six to eight hours of training, and first aid courses usually require eight to twelve hours for certification.



3. Other possible sources of training include emergency medical teams, licensed registered nurses, or licensed vocational nurses. They may offer the training you need, and they may be able to certify the trainees. Check with any such organization in your community.
4. If you choose a basic training with no certification, you may wish to keep the training very general. You may want to use a first-aid film and role-playing simulations as additional training presentations. General first aid information books are available from a variety of sources including the American Red Cross, Reader's Digest, State Departments of Public Welfare, etc. You may wish to provide a copy to each trainee and spend some time going over basic information.

Time considerations are one of the most important factors in your decision about CPR and first aid training. You must establish the amount of time which is available during the program; then decide on the method you wish to use for such training. You do not, however, want to over-emphasize this portion of the training, and you must constantly remind the trainees that emergency situations will be very rare in the course of respite care provision.

## SEIZURES

**PURPOSE:** To give the care provider trainees some basic information on types of seizures, their descriptions and some basic medication information.

**METHOD:** Presentation.

**MATERIALS:** Seizure Information Handout

**TIME:** 30-45 minutes.

### Notes to the Coordinator

Care providers will need some basic instructions on seizures, but once again you must emphasize that *the consumer family is the source of information about the family member's seizure history*. You may, however, choose to include a film or guest speaker to give some background on seizures, their recognition, and control. You may wish to consider one of the following as a possible speaker:

- 1) a client who is subject to seizures;
- 2) the parent of an individual who is subject to seizures;
- 3) a representative from the local epilepsy association;
- 4) a physician or nurse who works with seizure patients.

One of the most important aspects of this segment of the training should be to dispel the myth that seizures are "fits," and that practices such as placing an object in the individual's mouth to prevent him/her from swallowing the tongue are not to be used. A brief description chart is found on the next page and may be duplicated and given to each trainee.

You should also emphasize to the trainees that they must stay calm and follow any and all instructions that are given by the consumer family. Information about the client's seizure history can also be found on the Respite Care Registration Form (See p. 2.51).

## **SEIZURE INFORMATION**

### **TONIC-CLINIC SEIZURE/GRAND MAL**

This person may:

- fall
- stiffen
- make jerking movements
- develop difficult breathing
- have a pale or bluish complexion

During the seizure:

- help the person to a lying position and put something soft under the head
- remove glasses and loosen clothing
- clear the area of hard or sharp objects
- do not try to restrain the person; you cannot stop the seizure
- do not force anything into the person's mouth

After the seizure:

- the person will awaken confused and disoriented
- turn the person onto one side to allow saliva to drain from mouth
- do not offer the person any food or drink until fully awake
- stay by the person until he/she is fully awake
- encourage the person to rest

### **COMPLEX PARTIAL SEIZURE/TEMPORAL LOBE, PSYCHOMOTOR**

The person may:

- give glassy stare
- give no response or inappropriate response when questioned
- sit, stand, or walk aimlessly
- fidget with clothing
- appear to be drunk, drugged, or even psychotic

During the seizure:

- do not try to stop or restrain the person
- remove harmful objects from the person's pathway or try to coax the person away from such objects
- do not agitate the person in any way
- when alone, do not approach the person who appears to be angry or aggressive

After the seizure:

- the person may be confused or disoriented after regaining consciousness and should be left alone until fully alert

(HANDOUT)

**IT IS RARELY NECESSARY TO CALL PUBLIC AUTHORITIES UNLESS:**

- the person does not start breathing after the seizure (begin mouth-to-mouth resuscitation)
- the person has one seizure right after another
- the person is injured
- the person requests an ambulance

**DURING THE SEIZURE, MAKE NOTE OF THE FOLLOWING INFORMATION SO THAT YOU CAN GIVE A MEDICAL REPORT LATER:**

- the length of the seizure
- the person's behavior during the seizure
- any interruption of breathing
- skin color during the seizure
- any loss of bladder or bowel control
- eye movement or fixation
- person's behavior after the seizure

(HANDOUT)

## MEDICATION

**PURPOSE:** To give the care provider some practical experience in obtaining information from the consumer family about medication administration.

To give the care provider practical experience in administering various types of medication.

**METHOD:** Role-Play Exercise

**MATERIALS:** Copy of hypothetical authorization of administration of medicine. A variety of simulated medications: pills, tablets, liquids, etc. Spoons, cups, etc., (Whatever is necessary for administration).

**TIME:** 30-45 minutes

### Notes to the Coordinator

If the client will be taking any type of medication during the respite care period, the consumer family will have filled out specific medication instructions on the Respite Care Registration form (p. 2.51), and will have signed an authorization which will specify medication instructions. (See p. 2.59). *NOTE: Regulations about the administration of medicine vary from state to state and agency to agency. Check with your agency to see what guidelines must be followed. (For example, some states do not allow providers to measure dosages of medicine. Individual dosages must be measured by the consumer family prior to respite care and are left in individual containers for the providers to give to the client.)*

Any authorization, however, does not eliminate or replace the necessity for the care provider to ask the consumer family about exact instructions for the administration of these medications. Not only should the provider question the consumer family about medications which the client will be taking, but he/she should also ask for a demonstration of their administration. Ideally, the provider will be at the home at the time the medications are actually given so that he/she can administer them under the supervision of the family. If this is not possible, the provider should question the family extensively about:

1. which medications will be given
2. the exact dosages (pill, liquids, etc.)
3. frequency of administration (every three hours, once a day, etc.)
4. the usual manner in which the medication is given
5. the reason for giving each medication

The following is a list of important considerations which should be stressed in the discussion of medication administration:

1. Make sure you are giving the right medication. Read the container carefully, and if the instructions are not clear, ask a family member what the medication is, how often it is given, and the purpose for administering that particular medication.
2. Make sure the medication is being given at the right time.
3. Avoid handling any type of medication with your fingers. Pills and tablets should be poured into the container lid, and liquids should be poured into the spoon.
4. Always shake a bottle of medication in which there is a precipitate (a substance which separates itself from the solution).
5. Never mix liquid medications together, and make sure that medications can be given at the same time.
6. If the client should develop a rash, itching, or any other adverse reaction which might be attributed to the medication, contact the program coordinator immediately or, if possible, contact the family physician. *DO NOT GIVE ANOTHER DOSE OF THE MEDICATION UNTIL INSTRUCTED TO DO SO BY THE PHYSICIAN.*

The following is a list of abbreviations which may be found on prescription medicine:

gd	daily
b.i.d.	twice a day
t.e.d.	three times a day
q.i.d.	four times a day
p.o.	orally
h.s.	at bedtime
o.u.	each eye
o.s.	left eye
o.d.	right eye
q 2 h	every 2 hours
q 4 h	every 4 hours
sig.	give as directed
a.c.	before meals
p.c.	after meals
Gm	gram
Mg	milligram
gtt	drop

(HANDOUT)

## MEDICATION ADMINISTRATION EXERCISE

Using a fictitious medical authorization (sample below), the program coordinator will role play the consumer parent, and the trainee will:

1. interview/question the parent/guardian about the various medications, dosages, etc.
2. "administer" the medications (i.e. prepare the various dosages under the supervision of the parent/guardian).

In the role play, the trainee will question the "parent" about the medications and will simulate the administration of each type of medication under the direction and guidance of the consumer family member. It is important that the trainee actually administer the medications and not simply observe the parent/guardian. The parent can give specific instructions (example: tablets are poured into the container lid and are then placed in the client's hand).

Example:

Medical information form indicates that the client is subject to grand mal seizures and lists the following medications to be administered:

- a. Benadryl 5mg po q.i.d. (8 am, noon, 4 pm, 8 pm)
- b. Dilantin 25 mg po b.i.d. (9 am and at bedtime)
- c. Phenobarbital 1 tab. t.i.d. po (9 am, 1 pm, 6 pm)

In addition, the parent/guardian indicates that the client has a cold and has been taking two tablespoons of cough medicine three times a day.

(HANDOUT)

## BEHAVIOR MANAGEMENT

**PURPOSE:** To help the care provider manage situations in which a client is displaying some destructive or disturbing behavior.

**METHOD:** A presentation by a professional/counselor who can provide basic information and techniques for behavior management.

Role-play exercises.

Small group discussion; group discussion; question and answers.

**MATERIALS:** Handouts from speaker

List of hypothetical situations for role playing

A transparency may be used with overhead projector; a poster large enough for all trainees to read; blackboard if available.

**TIME:** 1-1½ hours

### Notes to the Coordinator

The purpose of this behavior management outline is to provide the respite care provider with some basic information that can be used in a variety of settings, with a variety of clients. The information is intended to help care providers manage situations in which a client is displaying some destructive or disturbing behaviors. THIS OUTLINE IS NOT INTENDED TO PROVIDE TRAINING THAT WOULD TRANSFORM EVERY RESPITE PROVIDER INTO AN EXPERT IN THE FIELD OF BEHAVIOR MODIFICATION. If the respite care coordinator wishes to expand upon this training outline, or if the scope of the respite care program is more rehabilitative in its orientation, a more comprehensive training program should be developed and employed.

Since most home respite care programs offer services only for short periods of time, it is not practical to expect the respite care providers to initiate drastic changes in behavior patterns which have been established over many years. Instead, the techniques presented here and the suggested discussions are meant to be only a part of the many skills that a well-trained and competent respite care provider will possess for service to the consumer families.

The following should be included in a training segment on behavior management. Based upon substantial research, the ideal approach to training staff members to use behavior management effectively is a combination of lecture (to provide some basic information) and active learning experiences (role playing, modeling). Topics to be included in your training program are:

1. *Use of positive reinforcement.* The most basic way to increase the frequency of desired behavior is by the administration of an immediate reward after the behavior is displayed. The reward may be a smile, a word of praise, a privilege, or a treat.



2. *In order for positive reinforcement to be effective, the chosen reward should be desirable to the client.* The client and his/her family would be the best source of information regarding the best choice or reward to use. (In some cases, special diets make it necessary to look for something other than the traditional candy as the reward.) Activities such as watching TV, playing a game, or listening to music may be rewarding to the client and require little or no expense on the part of the provider.
3. *Rewards should be contingent upon appropriate behaviors.* Whether the reward is given should depend solely upon the actions of the client.
4. *In most cases, immediate reinforcement is preferred, especially in a short-term setting (respite care).* Promises such as "if you go to bed now, I'll take you to the movies" should be avoided. Agreements or contracts of that type may be effective in long-term care situations, but they lose some of their reinforcement value in the short-term setting.
5. *Some of the most common ways to control undesirable behavior:*
  - a) Reward behaviors that are compatible with the desired behavior. Example: The client is a six-year-old child who wants to jump up and down on his bed instead of settling down to sleep. The reinforcement is given only when the child is lying down. The care provider may read a story to the child and stop reading when he is jumping.
  - b) Replace destructive or inappropriate behaviors with positive behaviors. Example: The client sits in the bathroom and continuously flushes the toilet. The care provider might take out a favorite toy or book and offer it to the client as an alternate activity. This technique is similar to Example a in that it involves replacing one undesired behavior with behavior that is more acceptable. Parents can provide information on what toys and activities the client especially enjoys.
  - c) Ignore non-injurious behaviors that seem to be attention-seeking in their nature. Attention-seeking behavior can be fairly easily recognized in that it usually ceases when the care providers pays attention to the client, but begins almost immediately when the attention of the care provider wavers. Example: A child shouts the name of the care provider until he/she responds. If the care provider can ignore this behavior and respond only when the child seeks attention in a more appropriate manner, the shouting may become less frequent. With some consumers, it is beneficial to explain that you will not respond to such behavior, but will be happy to respond when called in appropriate manner.
6. *The use of punishment.* In most settings, use of punishment is limited to specific situations in which there is great danger to the child or adult's health or safety. The use of the more positive techniques mentioned above has been shown to be effective in managing most behaviors encountered by respite care providers. Use of physical punishment has been shown, in many cases, to be a violation of the rights of the client and has negative side effects.

**Note:**

If during the screening of consumer families and clients, the coordinator encounters a situation that might require the use of corporal punishment, he/she must decide whether this consumer is appropriate or whether only specially trained providers should be used. Spankings, locking clients in rooms, physical restraint, withholding client's rights, etc., should be strongly discouraged, and the care provider should be warned that disciplinary and legal action problems might follow such activity.

**Procedures:**

Discuss the topics presented in the notes above, then introduce the following problems. The trainees should be divided into small discussion groups (6-10 individuals), and each group should try to come up with several alternatives for the care providers to use in these situations.

- Problem 1. John throws his food on the floor and says he only wants ice cream.
- Problem 2. Leslie continues to run outside and turn on the garden hose, flooding the dog house.
- Problem 3. George will not take off his clothes and take a bath.
- Problem 4. Julie will not take her medication.
- Problem 5. Ernie cries as soon as his parents leave the house on their first respite. He is still crying after 15 minutes, and ignoring his crying doesn't seem to help.
- Problem 6. Carolyn has been asked to put her toys away since it is nearly bedtime. After 15 minutes you check on her and find she has only put away one toy and still has 20 toys out on the floor.
- Problem 7. Bill is a wheelchair user. While he is coloring, he begins screaming every time he drops a crayon and will not retrieve it himself. You have come running 10 times in the last 15 minutes.

The respite coordinator can invent other problem situations that might be more appropriate to clients whom the trainees might encounter. After the respite program has been in operation for some time, real life anecdotes might replace these examples.

After the group of trainees has listed some of their suggestions, one member of the group will take the role of the respite care provider while another trainee plays the role of the client. Each member of the group should have at least one experience playing the client and several (if possible) experiences playing the role of the care provider. In this manner, the training will consist of more than lecture and will offer the trainees the opportunity first to think as a group (during the initial group discussion part of the exercise) and later to function as an individual in the simulation exercise.

Some suggested reading or sample texts that might be used to design a more comprehensive behavioral management program:

Bassinger, J.F., Fergusin, R.L., Watson, L.S. & Wyant, S.I. *Behavior modification: A programmed text for institutional staff*. Libertyville, Illinois: Behavior Modification Technology, Inc., 1971.

Walkder, J.E. & Shea, T.M. *Behavior modification: A practical approach for educators*. St. Louis, Mo.: The C.V. Mosby Company, 1976.

Watson, L.S. *Child behavior modification: A manual for teachers, nurses and parents*. New York: Pergamon Press, Inc., 1977.

Lynne Developmental Center. *Teaching methods and techniques for the autistic and autistic-like child and adult*. Richardson, Texas: Author, 1980.

## CARE PROVIDER-CONSUMER FAMILY INTERVIEWING EXERCISE II

**PURPOSE:** To help the care provider become familiar with the use of the daily routine format.

To give the care provider experience in "zeroing in" on topics that need special attention and to give the provider experience in asking the parent and client for physical demonstrations of such special areas of attention.

To give the care provider a second experience in interviewing techniques in general.

**METHOD:** Role playing exercise; small and large group discussions

**MATERIALS:** Pencil and paper; copy of each exercise vignette for each trainee; copy of blank "Daily Activity Record"; List of Important Aspects of Interviewing Exercise;\* training rating form for each trainee

\*May be a transparency used with overhead projector, a poster large enough for all to read, a blackboard if available, or copies to be distributed to each trainee.

**TIME:** 1½ hours

### Notes to the Coordinator

Two of the main objectives of the initial interviewing exercise were to have the trainee begin thinking in terms of client competencies and begin using behavioral descriptions rather than diagnostic labels. In this exercise, we further hope to help the care provider in gathering valuable information from the parent, information which will be needed to provide the optimal respite care.

One of the major functions of the respite care provider is to maintain the client's routines during a time when his/her parents and family members are not present. The client's daily routine can provide an outline which can be used by someone lacking experience as an interviewer. The care provider can use the outline as a guide, but he/she must be skillful enough to determine when to depart from the safety of the daily routine format and to ask pertinent questions, including demonstrations of specific techniques.

By using a time schedule format, it is easier for the family to recreate a typical day of the client. Often, when asked general questions such as "What needs to be done?", basic activities might be overlooked. A more structured format such as "What does John do at 7 a.m.?", "What does he do at 8 a.m.?" encourages the parent to be more specific. If the time schedule format is to be utilized, the care provider should be reminded that it is intended to help the care provider and the parent work together to determine what must be done in the parent's absence.

The importance of this format lies in the specific information that the care provider gets from the parents. For example, if the parent states that John's hearing aid must be put away and turned off at bedtime, the care provider should ask to be shown where to put it away and how to turn it off. It is unlikely that any care provider will

know the working of all types of hearing aids, leg braces, prosthetic devices, etc.; therefore, it is important that the parent demonstrates whatever maintenance the care provider will have to provide during his/her stay with the client.

The following excerpts will demonstrate two interview techniques. (You may choose to read these excerpts aloud to the trainees.)

Care Provider: "What does Sally do at 7 pm?"

Parent: "At 7 we usually remove her leg brace and help her with her leg exercises. The doctor says she needs a half hour of exercise every night before bed."

Care Provider: "Okay. Then what?"

Parent: "Then we put the brace back on, then she watches TV."

Care Provider: "What does she do next?"

Parent: "Well at 9 o'clock she goes to bed. You will have to remove her leg brace. Do you know how to take it off?"

Care Provider: "Sure. I've done respite care with other kids with leg braces. You know, if you've seen one, you've seen them all!"

In this exaggerated instance, the care provider seemed to rely on the "What does she do next?" format instead of taking the cue and accepting the parent's invitation to watch her remove the braces. The respite provider responded in a closed-minded and arrogant manner. Upon completion of this excerpt, ask the trainees to make suggestions of how the interview could have been improved. It is suggested that one trainee serve as a recorder so that no one person will record notes on all the interviews. Following the group discussion, two participants will act out the interview again, utilizing the group's suggestions to improve the interview. At the conclusion of the first interview, the trainer should have two trainees act out the second vignette. One trainee will play the role of the parent and the other the role of the care provider. After selecting the participants, the trainer should say:

"We will follow the same format, only this time \_\_\_\_\_ will play the role of the parent and \_\_\_\_\_ will play the care provider. As in the first case, the initial interview will contain some points that need improvement. At the conclusion of this interview, we will make some suggestions as to how the care provider might improve upon his/her skills. During the discussion (*Recorder*) will take down our suggestions, after which the actors again play out the interview in the suggested manner."

This procedure should be repeated until the trainer feels that the trainees have achieved competence in the task. Trainees should be encouraged to make comments and suggestions during the discussion section. After the second enactment, you may wish to reiterate briefly the improvements made upon the first interview. The trainer should be cautious that no one takes offense with the criticism of the other trainees' action, acting, or reading ability. The vignettes were specifically designed not to be

taxing on the participants, their reading abilities, or their acting abilities. A sense of humor on the part of the trainer and the participants will enable this exercise to move along better.

In this second excerpt, we shall see a care provider responding in a more appropriate manner.

Care Provider: "What does Sally do at 7 pm?"

Parent: "At 7 we usually remove her leg brace and help her with her leg exercises every night before bed.

Care Provider: "I have had some experience with people wearing leg braces. It would be best if you would show me how to remove Sally's leg brace and the type of exercises that you do with her. if Sally wouldn't mind, may we do a little of the exercises so that I'll get them right?"

At this point, we see the respite care provider has noted that this portion of Sally's routine is important. Some specific information and demonstration from the parent and Sally are necessary.

Parent: "To remove the leg brace, you must first undo this latch."

Care Provider: You had better let me try it so that we'll have no problems later." (Care Provider undoes latch) "Is this right?"

Parent: "Make sure you keep her leg straight when you do that."

Care Provider: "Why don't you put my hand on her leg and show me what you mean."

The care provider is demonstrating that he/she cares about performing the activity correctly. This shows a respect for the parent's expertise with the child. Some care providers may fear looking stupid in the eyes of the parent. It would seem that the concern of the care provider and the respect shown to the client and the parent will override any lack of knowledge.

There are certain topics which, when discussed, should call for a deviation from the daily routine format. These topics are listed on the handout page which follows.

**Medication:**

Does the client administer his/her own medication? If so, how much assistance does he/she require?

When is it given?

How much?

How is it administered? (e.g. Is it diluted in juice? Given with a spoon or cup?)

Do you have to crush the pills? If so, how do you do it?

**Prosthetic Devices:**

Does the client put on his/her own prosthesis? How much assistance is needed?

How do you put it on and how do you remove it? (In the case of the prosthetic devices, it is advisable to have the parent and the client physically demonstrate the process and put the care provider through the actual procedures.)

Is there daily, routine maintenance or cleaning of the device?

**Hearing Aids:**

Does the client put on his/her own hearing aid? How much assistance is needed?

Does the volume or fitting need to be adjusted?

Will the batteries need changing? If so, where are the spare batteries and how do you replace them?

**Special Toileting Procedures:**

Is the client on a timed toileting schedule?

Does the client wear a catheter? To what extent, if any will the client need help with his/her catheter? (How do you put it on? In what fashion is it secured? What maintenance is to be performed?)

**Special Feeding Procedures:**

Does the client need to be fed?

Does the client use any special utensils, placemats, or seating arrangements?

Does the client need his/her food chopped, blended or served in a special fashion?

Is he/she on a special diet? If so, what are the restrictions of the diet?

(HANDOUT)

**Communication Disorder:**

Does the client have a special way to communicate?

Does he/she use sign language? If so, what signs in particular would be useful?

Is there a personal method of communicating needs? (e.g. pointing at objects)

Is there a problem with the clarity of his verbal communication? (e.g., "When John says 'WAAA,' it means he wants a glass of water.")

**Bedtime Routines:**

Does the client have any special bedtime routines? (e.g., does he/she sleep with a light on?)

Is there uninterrupted sleep?

(HANDOUT)



The topics on the handouts are some examples of information the respite care provider should listen for when interviewing the parents of a client. When one of these or another important issue arises, the care provider should stop asking general questions concerning the client's daily routines and direct his/her attention to these more specific issues. *IT CANNOT BE OVEREMPHASIZED THAT THE CARE PROVIDER SHOULD ASK THE PARENT TO DEMONSTRATE ACTIVELY AND PHYSICALLY ANY SPECIAL PROCEDURES THE CARE PROVIDERS MUST BECOME FAMILIAR WITH PRIOR TO THE PARENT'S DEPARTURE.* The actual "Show me how you do it" phase of the interview is more valuable than information gathered on a form or questionnaire.

When such a special, care-related topic does arise, the care provider should ask questions such as:

"What do you suggest I do when \_\_\_\_\_?"

"Can you anticipate any specific problems I might encounter when I do?"

"How do you suggest I best deal with \_\_\_\_\_?"

If the care provider asks the right questions, he/she will get enough information from the parents to make the respite a safe and pleasant experience for all involved. In dealing with their handicapped relative 24 hours a day for 365 days each year, parents sometime take for granted the daily activities that they perform with their child. It is possible that some of these events that are performed almost habitually might be forgotten when giving instructions to a respite care provider. It is through a good pre-respite interview that some of these activities are remembered. It is through the asking of questions such as "What problems might I encounter?" that parents are sometimes reminded of problems they once encountered. Sharing these experiences will help the respite care provider become more capable of providing safe and effective services.

After reviewing the material discussed in the previous section concerning such topics as the use of daily routine format and keying in on important topics, the trainees should have a better understanding of the interview process and the goals of the pre-respite care interview.

This exercise is designed to be conducted midway through the training. In order to maximize the effectiveness of the interview exercise, it is important that they be alternated with periods of instruction on other topics.

### **Room Arrangement**

The trainees and trainer should be seated in a semi-circle with two chairs left in the middle for the people who will be participating in the role play.

### **Procedures**

"In this exercise, we will again engage in a role play situation. To demonstrate, I will play the role of the respite care provider, and I need one volun-

teer (or you can use another person who is assisting you with the training) to play the role of the 'parent.' In this interview, the care provider will make several mistakes. Pay close attention for we will discuss the errors made and then redo the interview in an improved manner." (Role play participants read the script and act out the first interview.)

## DAILY ACTIVITY RECORD

Client \_\_\_\_\_ Care Provider \_\_\_\_\_ Date \_\_\_\_\_

6AM _____ _____ 7AM _____ _____ 8AM _____ _____ 9AM _____ _____ 10AM _____ _____ 11AM _____ _____ 12PM _____ _____ 1PM _____ _____ 2PM _____ _____ _____	3PM _____ _____ 4PM _____ _____ 5PM _____ _____ 6PM _____ _____ 7PM _____ _____ 8PM _____ _____ 9PM _____ _____ 10PM—6AM _____ _____ _____ _____
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This record form can be used as a guide for the care provider in his/her interview with the parents or relative of the client. It is also helpful for the care provider,

especially when respite care is for several days. It should be emphasized that this type of format is meant to offer structure to the interview.

## **Important Aspects of Exercise II**

1. **GET ACTIVELY INVOLVED IN THE INTERVIEW**—When necessary, have parents and the client show you how they do things.
2. **SHOW RESPECT FOR THE CLIENT AND HIS/HER FAMILY**—They have been living with the handicapping condition for a long time and will live with it after you have completed your respite service.
3. **PAY ATTENTION TO TECHNIQUES AND ROUTINES THAT HAVE BEEN OR ARE BEING USED WITH THE CLIENT**—Through consultation with experts, personal experiences and through trial and error, the family has developed methods of effectively compensating for the handicapping condition. Don't try to be another expert consultant; this is not your job.
4. **USE A TIME-SCHEDULE FORMAT TO OBTAIN INFORMATION**—Don't be mechanical in your use of this type of format.
5. **KNOW WHEN TO DEVIATE FROM YOUR FORMAT**—Be aware of key issues which need special attention in the interview, such as:
  - A. Medication
  - B. Prosthetic Devices
  - C. Special Toileting Procedures
  - D. Special Feeding Procedures
  - E. Bathing Routines
  - F. Bedtime Routines
6. **TRY TO ANTICIPATE PROBLEMS THAT MAY ARISE OR INFORMATION YOU MAY NEED AT A TIME WHEN THE PARENTS ARE NOT PRESENT.**

(HANDOUT)

### **Interview 1**

Care Provider: "Don't worry. I have taken care of this kind of kid before."

Parent: "Mary uses manual communication; do you know sign language?"

Care Provider: "I don't believe in that stuff. No one will ever be able to understand her in the 'real' world. Anyway, I don't think I'll have much trouble understanding her speech."

Parent: "Well her speech therapist says we should use sign language with Mary so she'll learn it better and faster."

Care Provider: "Speech therapists! They don't know what is best for a kid. Take my advice, she'll be better off if she is made to talk for what she wants."

(HANDOUT)

### **Interview 2**

Care Provider: "Okay Mrs. Smith, now what does Bill do after supper?"

Parent: "He usually likes to help clear off the dinner dishes."

Care Provider: "It must take forever for him to clear off the table in that wheelchair. Maybe it would be better this one time if I cleared off the dishes and just let Bill watch TV."

Parent: "Bill really does like to help."

Care Provider: "Yeah, I know, but I get sort of impatient when I have to wait for someone who is slow. I'm sure that Bill wouldn't mind my clearing the dishes this one time."

(HANDOUT)

### **Interview 3**

Care Provider: "Say, I once watched a kid who ate with one of those funny looking spoons. What a mess that kid made! I hope that yours is a better eater than that one. Maybe you know the kid. It was Eddie Jones. He spilled food all over my new sweater."

Parent: "Well I'm afraid that Mike isn't that neat himself. He is just learning to use the spoon. I have a smock that I wear when Mike eats so that I can help him without getting food on myself."

Care Provider: "Boy! I told them at the Respite office that I didn't want any more messy kids! I have half a mind to go over there right now and tell them a thing or two."

(HANDOUT)

#### **Interview 4**

Care Provider: "What does Jay do at 6 p.m.?"

Parent: "Usually he has his dinner."

Care Provider: "What happens after dinner?"

Parent: "Usually, he washes up."

Care Provider: "And what does he do after washing?"

Parent: "He likes to watch TV."

Care Provider: "What does he do after TV?"

Parent: "He takes his medicine and goes to bed."

Care Provider: "Could you fill out the rest of this form for me? I'm a pretty bad speller and that medicine stuff is a real pain."

Parent: "Do you know how to measure out the correct dosage? Jay's doctor says he must get the exact dosage."

Care Provider: "It must say so on the bottle. I can handle it!"

Parent: "Are you sure? We sometimes have had trouble with it?"

Care Provider: "Sure I'm sure! Then what does he do?"

Parent: "He goes to bed. Oh, I forgot to tell you. He has a snack in the evening, peanut butter on crackers."

Care Provider: "Now you tell me! I'll have to rewrite this form to put that in. Why don't you just fill out the whole thing; this way, my boss will be happy and it'll be easier for the both of us."

(HANDOUT)

### Interview 5

Parent: "I notice that you smoke. Please be careful! Terry has started several fires when he has found matches lying around. It hasn't happened in a while since we have started this behavior program that a psychologist suggested."

Care Provider: "I've taken Introductory Psychology at school and I know all about pyromaniacs. I even did a paper on fire setters. I got a C+ on it. I would have gotten an A, but the teacher took off for spelling and for the paper being late."

Parent: "Let me tell you what we do with Terry."

Care Provider: "Oh, don't bother. You will only be gone for a few hours and nothing will happen. Besides, I did a lot of research. Did you know that they did this study in 1978 . . . ."

Parent: "But Terry's problem is not like that."

Care Provider: "Probably some psychological hangup. But don't worry, I'll just talk things out with him if there is any problems. My psych teacher told me that I might make a good therapist some day. Have you ever gone to see a shrink?"

Parent: "What does that have to do with my son?"

Care Provider: "Everything, man! You know what Freud said . . . ."

(HANDOUT)

After the trainees have had the opportunity to play a role in this exercise, the trainer should go over general points about the interview process. The trainer has provided an outline (Important Aspects of Exercise II). This outline can be converted to a transparency, copied onto a blackboard or large sheet of newsprint, or photocopied and distributed to the trainees.

The trainer should go over each point and encourage the trainees to offer input on the six recommendations listed. At the conclusion of the discussion, the trainer may once again wish to discuss important aspects of Exercise I. It should be apparent to the trainees the importance of gathering from the client and his/her family the information needed to provide effective respite care.

At the conclusion, a Training Rating Form, identical to the one used in Exercise I, should be distributed. The trainees should evaluate their experiences and feelings about this exercise.

## **TRAINER'S GUIDE TO INTERVIEW DISCUSSION**

Each vignette has been designed to emphasize specific interview skills and procedures. The trainer should refer to the comments provided that pertain to each interview. These comments should be used to assist the trainer in guiding the trainees to focus upon the most important aspect of each interview.

### **Interview 1**

In discussing this vignette, it is hoped that the trainees will note the manner in which the respite care provider sets him/herself up as an expert. The care provider is a service provider and not a consultant. The care provider should have had the parent or Mary show him/her some basic signs if he/she was not familiar with sign language.

### **Interview 2**

In this interview, the care provider shows a lack of respect for Bill and his parents. The care provider is also disregarding Bill's daily routine by suggesting a drastic change. Instead, the care provider should have asked the parent if there was a certain way that he could be of assistance to Bill in his chores. Also, the care provider should not alter the client's home situation to meet his/her own impatience.

### **Interview 3**

In this interview, the care provider made numerous errors. Initially he/she seemed to mock the client, calling his spoon "funny looking." Next, the care provider talked about another client by name. It should be stressed that there be some degree of confidentiality in the care provider's discussions with parents. In his/her final statement about not wanting to take care of any more messy kids, he/she might, indeed, have a bad temper.



It would not be surprising if the parent dismissed the care provider prior to his/her working with the client.

#### **Interview 4**

In this case, our care provider relied very heavily on the form he/she was filling out. By taking a "Just the facts, Ma'am" attitude, he/she was passing up important details (e.g. administration of the medicine). It seems rather obvious that the parent would have felt better if the care provider demonstrated that he/she could administer the medication rather than just taking his/her word that "I can handle it."

#### **Interview 5**

In this instance, the care provider was so concerned with telling his own stories and playing psychotherapist that he/she did not gather any information from the parent. Instead of "zeroing in" on the behavior program that has apparently been successful with Terry, the care provider went on and on and on. The care provider also exceeded his bounds by asking the parent, "Have you ever seen a shrink?" Information like that has no relevance to the issue of this respite care and is totally inappropriate.

## TRAINING RATING FORM

TRAINING TOPIC: Care provider-Consumer Family Interviewing Exercise II. I would rate this training exercise as follows:

BORING					INTERESTING	
1	2	3	4	5	6	7
CHAOTIC					ORDERLY	
1	2	3	4	5	6	7
USELESS					USEFUL	
1	2	3	4	5	6	7
POOR LEARNING EXPERIENCE					GOOD LEARNING EXPERIENCE	
1	2	3	4	5	6	7
ANXIETY PRODUCING					NON-ANXIETY PRODUCING	
1	2	3	4	5	6	7

Comments about this training exercise: \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

(HANDOUT)

## **CARE PROVIDER-CONSUMER FAMILY INTERVIEWING EXERCISE III**

**PURPOSE:** To give the care provider a third experience in interviewing techniques and information gathering

**METHOD:** Role playing exercise  
small and large group discussions

**MATERIALS:** Pencil and paper  
Copy of client descriptions for each "parent" trainee  
Daily activity record-blank  
"List of Important Aspects" for this exercise; Training rating form

**TIME:** 1-1½ hours

### **Notes to the Coordinator**

This is the last of the three interview exercises, and the format closely follows that of the first exercise. The material covered in this exercise is a combination of the initial exercises and should closely resemble a shortened version of a real interview with the parents of the handicapped client.

During these last stages of training, the trainees will feel more at ease in a role play situation. At this point, the trainees have been exposed to material in experiential and didactic formats and will be capable of conducting higher quality interviews. The trainees are aware of the major issues involved in interviewing families of handicapped clients and will take their experiences and knowledge out into the field.

The room should be set up as it was in Exercise I. If there is an odd number of trainees, one group could be formed with three members (two "parents" and one care provider).

### **Procedures**

Explain that this exercise is similar to the first interviewing role play. Once again ask that one person take the part of the parent and the other the part of the respite care provider. Point out that the description will be longer and more comprehensive than in Exercise I. Ask the groups to move into the areas of the room designated for this exercise. Distribute copies of the client summaries to the parent member of each group. Give the parent role player a few minutes to become familiar with the material.

Instruct the person playing the role of the care provider to spend about 20 minutes interviewing the parent. Remind the care provider to stress the competency of the client: 1) be aware of the 6 things on the chart; 2) establish some interpersonal contact with the "parent"; 3) stay away from diagnostic labels; 4) use but don't overuse the daily routine for interview; 5) depart from the format when some important issue comes up; and 6) ask the parent to show how it is done.

Begin the interviews and allow about 20 minutes. After the time has elapsed, reverse roles so that each person gets to practice being a care provider.

The trainer should plan to spend a few moments with each group of trainees to reassure them and to observe techniques and answer questions. After allowing about five or ten minutes for discussion, pass around the second set of client summaries. Follow the same procedures as in the first part of the exercise.

Before the training session, prepare a chart or write on a chalkboard listing the 6 important aspects to be remembered by the care provider when conducting an interview.

This exercise can also be done in groups of 3 with 2 people role playing and one observing and offering a critique when the role play is completed.

At the conclusion of the role play and the small group discussion, the entire group should take a short break. After about a ten-minute break, the trainees should reassemble and sit in a circle with the trainer. The members of the group should then be encouraged to discuss the exercise. Particular emphasis should be placed upon:

1. The difference in confidence felt after this exercise
2. Differences in competency
3. How this session differed from the other two

Procedural and technique-oriented questions and comments should also be brought up at this time. Since this is the last interviewing exercise, the trainees should also be encouraged to comment on areas that they felt were not adequately covered.

**Client 1**

Points to be gathered in this interview:

Name: Michelle

Age: 12

Hobbies: Michelle enjoys playing ball-bouncing games. If left on her own, she will play with a ball for long periods of time. She also enjoys watching cartoons on television, although she will only watch for brief periods (around 10 minutes).

Daily Activities: Michelle is going to an elementary school in the neighborhood. She is in a special education class and is involved in few school activities involving people outside of her special class (e.g. recess).

Medical Problems: No serious medical problems. She is given a 10mg dose of medicine X at night to help her fall asleep.

Physical or Sensory Problems: Michelle freely moves about with little problem. Her coordination is not at the expected level for children her age, but she can run, ride a three-wheel bicycle, and play on swings. Michelle displays little speech. She can only say four or five words, but she does have an understanding of simple household words (e.g. spoon, bike, stop, hot, milk, etc.).

Household Skills: Michelle can feed herself with a fork and spoon, but she cannot cut her meat. She enjoys helping dry the dishes, and the family uses plastic dishes at most meals since she drops several dishes each week. Occasionally, Michelle will have a toileting accident. She needs to be reminded before bedtime in particular to go to the toilet.

Personality Traits: Michelle is very affectionate with everyone she meets. Her family members are very warm and affectionate, and therefore, Michelle is not afraid of strangers but is very easily frightened by dogs and cats. At times, she will become frustrated when she cannot make her needs understood.

Daily Activities: Respite care to last from 7:00 a.m. until 12:00 midnight.

(HANDOUT)

- 7:00 a.m.: Wake up and get dressed. Michelle needs help tying her shoes and should be reminded to go to the toilet.
- 7:30 a.m.: Breakfast. Michelle eats whatever everyone else is having at that meal. Her personal favorite is Frosted Flakes. After breakfast, she takes her multi-vitamin which is ground up and put in her juice. At times, she has difficulty swallowing pills.
- 8:00 a.m.: School bus picks her up in front of the house. She needs to be watched carefully as she, at times, will get excited and run into the street and meet the bus.
- 2:30 p.m.: School bus drops off Michelle in front of the house. Someone must wait for her at the bus stop since she might go into the street.
- 2:30 p.m.-4:00 p.m.: Michelle usually plays on the porch with her ball or crayons. She enjoys having the radio playing while she plays.
- 4:40 p.m.: Wash-up time and preparation for dinner. Michelle needs to be observed when she washes because she will often use very hot water and has, in the past, burned her hands.
- 5:00 p.m.: Michelle helps clear the table. She will dry the dishes after they are washed.
- 6:00 p.m.: After dinner, Michelle takes her bath. She is prone to inner ear infections, so water should not get into her ears; a special technique to wash her hair is necessary. (Care provider should ask the parents to show how they wash her hair.)
- 6:30 p.m.: Michelle is given her medication, 10mgs of X in a liquid form. The liquid is poured in the cup up to the 10mg marker.
- 6:30 to 7:30 p.m.: Michelle likes to color, play with her ball, or sometimes watch television.
- 7:30 p.m.: Michelle goes to bed and usually has a bedtime story read to her. Her two favorite stories are *Goldilocks* and *The Three Little Pigs*. (She will need to be reminded to go to the toilet.)
- 7:45 p.m.: Michelle should go to sleep. Usually, she climbs out of bed several times. She should be walked back to her room immediately after she comes out. She will give up after two or three attempts.
- During the Night: Michelle usually sleeps through the night, but on occasion, she will wake up crying. Usually this is because her bed is wet, or she has had a bad dream. She needs to have someone hold her hand and stay with her for about 10 minutes to soothe her.

(HANDOUT)

## **Client 2**

Points to be gathered in this interview:

Name: Fred

Age: 43

Hobbies: Fred enjoys stamp collecting, listening to music on the phonograph, watching television, and reading.

Daily Activities: Fred attends a sheltered workshop during the day. He is employed as a Quality Control Inspector, checking products for damages or improper construction. He also attends social activities sponsored by the local chapter of United Cerebral Palsy.

Medical Problems: Fred has some serious problems with the swallowing of foods and with his digestive tract. He is on a special diet and must have his food prepared in a soft manner to assist in digestion and swallowing. He takes 100mgs of medication X at 8:00 a.m. and 8:00 p.m.

Physical or Sensory Problems: Fred uses a motorized wheelchair operated by a hand switch. He has limited use of his left hand and little to no use of his other limbs. His speech is difficult to understand at first, but after some careful listening and accommodation on the part of the listener, he can be understood.

Household Skills: Fred needs help to get in and out of his wheelchair. The person helping him should remember to lock the wheels of the wheelchair before helping Fred out. Fred is capable of describing to the person helping him how he should be lifted. He needs help getting dressed. Fred has been able to purchase electronic equipment to assist him in using the telephone, opening the door, turning on the television, etc. He is able to shave himself with a special adaptive electric razor, but needs help taking a bath.

Personality Traits: Fred is extremely independent. He has lived with his parents for the past three years after spending most of his life in hospitals and institutions. He realized that there are skills he does not possess, and he needs help in these areas, but he is very sensitive if others feel sorry for him or treat him in a patronizing fashion. Although Fred has had only limited education, he has read a great number of books and is presently writing his autobiography.

Daily Activities: Respite care to last from 5:00 p.m. to 10:00 p.m.

5:00 p.m.: Fred arrives home from work. The bus driver assists him from the minibus, and Fred is able to go up the ramp and enter his house.

5:30 p.m.: Fred needs help in washing up for dinner and changing from his work clothes to clean clothes.

6:00 p.m.: Dinner is prepared in accordance with Fred's special diet. (The diet is posted on the refrigerator door for reference.) Food must be served in a soft form, and Fred uses special utensils and a non-skid bowl. Fred's throat must be

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massaged (care provider should ask someone for some demonstration) to make sure that food is swallowed properly.

6:30 p.m. until Bed: Fred usually will occupy himself with his reading, stamp collecting or other activities.

8:00 p.m.: Fred receives his medicine in liquid form.

8:00 p.m.: Fred does whatever he wants until bed. Before bed he will need assistance with changing into his pajamas and going to the toilet. Fred also needs to be helped into his bed and have the rails raised for his safety (care provider should ask someone for some demonstration at this point). Until Fred's parents arrive, the care provider should keep the door to Fred's room open so that he can be heard if he needs to go to the toilet or needs any other form of assistance during the remainder of the evening

(HANDOUT)



### **Client 3**

Points to be gathered in this interview:

Name: William

Age: 15

Hobbies: William likes to ride his bicycle, roller skate, put together jigsaw puzzles, swim, and watch sports on television. He is an avid fan of Reggie Jackson and has his pictures and posters hung all over his bedroom.

Daily Activities: William goes to a local elementary school where he has recently been mainstreamed into a regular class for part of the day. He receives special instruction during the other part of the school day.

Medical Problems: William is a diabetic who requires an injection of insulin each morning. This medical condition has necessitated his being kept on a very strict diet. He also needs to have his blood tested for glucose level several times during the day (times listed on a chart on the kitchen cabinet).

Physical or Sensory Problems: William is very active, but due to his diabetes, is gradually losing his vision. At present time his vision is generally good (although he wears glasses), but when upset or tired, he reports some difficulty with his sight. These problems have yet to affect his play. William is also a slow learner. He has yet to learn how to monitor his own diet and will often try to sneak prohibited foods when he is not observed closely. He is doing school work on a level equal to that of children who are two to three years younger than he.

Household Skills: William is able to dress, bathe, toilet and feed himself with no assistance. He doesn't like to, but he does make his bed, clean up his room and take out the trash.

Personality Traits: William is friendly. Usually a stranger can get off to a good start with William by talking with him about baseball or sports in general. William poses little or no behavior problems, but he has to be closely watched so that he doesn't try to eat candy bars or other foods prohibited by his diet.

Daily Activities: Respite to last from Saturday morning into Saturday night.

8:00 a.m.: William wakes up and watches television.

8:30 a.m.: Visiting nurse will come and check William's blood count and administer insulin.

9:00 a.m.: Breakfast is prepared according to instructions given by the visiting nurse.

10:00 a.m.: Weather permitting, William will go out and play with the children on the street. If not, he usually watches TV and works on a puzzle or plays his baseball card game.

12:00 noon: Get a urine specimen from William. The urine should be checked to determine the glucose level with strips of litmus paper. (Care provider should ask for demonstration and observe closely how the urine is checked.)

12:15 p.m.: William has lunch.

12:30 p.m.: William should take some time to rest or play quietly. He sometimes will work on his homework during this time.

2:00 p.m.: William again goes out and plays.

4:00 p.m.: Urine should again be checked. If glucose level is high, he should be given some orange juice and a peanut butter sandwich.

6:00 p.m.: Urine checked and dinner prepared.

6:30 p.m.: William helps with the dishes and cleaning up after the meal.

7:00 p.m.: William plays in the house or watches TV until bed.

9:30 p.m.: Urine should be check and if glucose level is high, William will need a snack.

10:00 p.m.: William goes to bed.

11:00 p.m.: Parents will arrive home.

(HANDOUT)

#### **Client 4**

Points to be gathered in this interview:

name: Brian

Age: 7

**Hobbies:** Brian likes to play with toy cars, trucks and other objects that have wheels. He enjoys watching records spin on the record player, and seems to enjoy the music. Often, he will just let the record player run without a record on it. He also enjoys playing with water in the sink, toilet or bathtub.

**Daily Activities:** Brian attends a special private school. He also is receiving speech therapy three times a week and sees a psychologist for play therapy once a week.

**Medical Problems:** Brian has grand mal seizures several times per week. He gives no recognizable warning that he is about to lapse into a seizure. Recently, his medication was changed to 50 mgs of X three times a day. This is a substantial increase from his previous dosage. Although his seizures have diminished in frequency, he has become more listless and often falls asleep at school or at home.

**Physical or Sensory Problems:** Brian does not speak at all. His doctors have found no physical problem that impedes his speech or that has hampered his hearing. Brian does communicate in primitive sign language (example: he will put his hand up to his mouth whenever he wants to eat or drink). At other times, he will sit sullenly on the floor with tears in his eyes expecting someone to bring him something (e.g. a toy, cookie). He has no problem in walking; in fact, his coordination seems to be quite good for a child of his age.

**Daily Activities:** Respite to last from 6:00 p.m. to Midnight.

6:00 p.m.: Brian takes his final dose of X, 50mgs and must be watched to make sure that he swallows the medicine because he has, at times, run into the bathroom and spit it out. A glass of apple juice is given immediately after the medicine to insure that all medicine is swallowed.

7:00 p.m.: Brian takes a bath and must not be left unattended in the tub since he enjoys turning the water on and allowing the tub to overflow.

7:30 p.m.: Brian enjoys playing his records before bed for about a half hour. He is capable of operating his player by himself.

8:00 p.m.: Record player should be turned off and taken into the parents' bedroom. Brian sleeps with a night light on in his room. Every 15 minutes or so, the care provider should quietly walk by his room to make sure that he is not out of bed playing with his toy cars.

**Midnight:** Parents should arrive back at home.

**NOTE:** If Brian has a seizure, do not try to hold him down or constrict his movement. Do not put your finger in his mouth. The seizures should only last about 30-45 seconds. After his seizure is completed (you know it is over by the lack of tension

in his body—he will seem quite relaxed), he may be especially disoriented. He usually is given a blanket from his bed and allowed to lay on the floor for about 10 minutes. After 10 minutes or so, he will probably get up on his own and change his clothes since sometimes he soils his pants during or after the seizure. He needs help getting cleaned up and getting some clean clothes. IF THE SEIZURE LASTS IN EXCESS OF TWO MINUTES, THE DOCTOR SHOULD BE CALLED (NUMBER IS ON THE PAD NEXT TO THE PHONE), AND THE PARENTS SHOULD BE CONTACTED.

(HANDOUT)

## **Client 5**

Points to be gathered in this interview:

Name: Janet

Age: 6

Hobbies: Janet is generally not very active unless someone spends time playing with her. She likes to feel of soft stuffed animals against her hands and face. Since Janet spends most of her time in her crib, she does not seek out any outside stimulations or activity.

Daily Activities: Janet does not attend any daily activities at present. Due to her frequent illnesses, she has not begun any form of school.

Medical Problems: Janet has a neurological disorder which prevents her from walking or sitting up on her own. She can be propped up in a sitting position for up to 30 minutes at a time by the use of cushions and a special chair. She is highly susceptible to prolonged respiratory infections and has several severe allergies to foods and medicines.

Physical and Sensory Problems: Janet is not capable of speech. She also cannot use sign language since she does not have control of the movements of her hands. She has begun to learn the use of a communication board upon which there are pictures of some common objects. Janet will stare at the picture of the objects. The person who wishes to communicate with her will then say the name of the object that they believe she is staring at. She will indicate yes or no by a nod of the head.

Household Skills: Janet needs almost total care. She can drink with a straw, but must be fed solid foods. She needs to be taken to the toilet periodically (every two hours) or upon her request via the communication board. She also needs to be dressed and have things brought to her.

Personality Traits: Although her communication is limited to the communication board, Janet is capable of smiling when she feels happy and satisfied. She enjoys physical contact (e.g., hugs) and personal stimulation. She very rarely demonstrates her displeasure and shows patience when others are unable to understand her communications.

Daily Activities: Respite care to last from 2:00 p.m. until 9:00 p.m.

2:00 p.m.: Janet usually begins her nap at this time. She often requests that someone read her a story before her nap. The shades in her room should be drawn prior to her nap.

3:00 to 3:30 p.m.: Janet is usually awake by now. She usually needs to go to a specially designed toilet in the adjoining bathroom. (Care provider should ask to be shown the bathroom and have the parent(s) demonstrate how it should be used, i.e., positioning of Janet.)

3:30 p.m.: Janet receives 250mgs of medication X in liquid form.

- 3:35 p.m.: Janet is set down in her special chair and positioned in front of the TV set in the living room to watch part of "Sesame Street."
- 4:00 p.m.: Janet is brought back to her bed. Usually several of her stuffed toys are left in the bed with her so that she may play. While she is in bed, dinner is prepared.
- 5:00 p.m.: Dinner. Janet is not able to chew meats, so her meals should consist of creamed vegetables, ground beef cooked in the broiler and a milkshake. She must be fed. She drinks the milkshake from a straw and is very proud of this accomplishment. The glass needs to be held down and straw positioned near her mouth. For the meal, Janet sits in her chair in the kitchen.
- 5:30 p.m.: Janet should be taken to the toilet. Afterwards, she should be moved back to bed and given a sponge bath with a wash cloth and some warm soapy water. The heat in the house needs to be at least 74 degrees (thermostat in the hall). She must be thoroughly dried off before putting her pajamas on.
- 6:00 to 7:00 p.m.: Janet will play with the toys in her bed.
- 7:00 p.m.: Janet usually likes to watch television. The portable TV can be set up in her room on top of her dresser so that she can see it. She enjoys watching "BJ and the Bear" on Channel 4.
- 8:00 p.m.: Janet is taken to the toilet. She sometimes requests a glass of water before going to sleep. She also should be given 250mgs of medicine X and 2 teaspoons of medicine Y.
- 8:15 p.m.: Janet likes to be read to again. Some of her favorite books can be found on her dresser. She will nod when presented with a book she prefers.
- 8:30 p.m.: By this time, she is generally asleep.
- 9:00 p.m.: Parents return.

(HANDOUT)

### IMPORTANT ASPECTS OF EXERCISE III

1. Establish rapport.
2. Stress the client's competencies.
3. Find out the nature of the client's handicap.
4. Get actively involved in the interview.
5. Show respect for the client and his/her family.
6. Pay attention to techniques and routines that have been or are being used with the client.
7. Elicit parent's suggestions of how you might "break the ice" with the client.
8. Don't rely upon professional jargon.
9. Know when to deviate from your format.
10. Try to anticipate problems that may arise or information you may need at a time when the parents are not present.

### TRAINING RATING FORM

TRAINING TOPIC: Care provider-Consumer Family Interviewing Exercise III. I would rate this training exercise as follows:

BORING						INTERESTING
1	2	3	4	5	6	7
CHAOTIC						ORDERLY
1	2	3	4	5	6	7
USELESS						USEFUL
1	2	3	4	5	6	7
POOR LEARNING EXPERIENCE						GOOD LEARNING EXPERIENCE
1	2	3	4	5	6	7
ANXIETY PRODUCING						NON—ANXIETY PRODUCING
1	2	3	4	5	6	7

Comments about this training exercise: \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

## ADMINISTRATION INFORMATION

**PURPOSE:** To familiarize the care providers with the various forms and paperwork which are necessary for record keeping and the smooth functioning of the overall program.

To give the trainee some practical experience in the reading and filling out of necessary forms.

**METHOD:** Coordinator's presentation  
Exercise in filling out/reading forms

**MATERIALS:** Copies of all forms which will be used by your program; one copy of each form for each trainee

**TIME:** 1-1½ hours

### Notes to the Coordinator

The variety of forms to be used in providing respite care will depend on the individual program, and only you will be aware of exactly which forms will be used for your program. Some sample forms were included in Unit II of these materials, but others will have to be developed specifically for your program. Requirements will vary from state to state and agency to agency.

The purpose of this exercise is to familiarize YOUR trainees with the forms required for YOUR program, so this exercise and your presentation should include:

1. Forms that you will be giving to the provider prior to respite care services. This may include the family background, medication forms, and any other forms you have filled out with the consumer family or which the consumer family has filled out.
2. Forms which the provider will be filling out with the assistance of the consumer family and/or client. This may include daily routine charts, feeding check-lists, etc.
3. Forms that the provider will have to fill out after respite care services have been given. This would include any evaluation or follow-up forms that have been designed for your program.

This segment of the training will also be ideal for explaining any additional administrative information that might be necessary: What to do if the provider becomes ill during respite care? What to do if an emergency situation arises during the provision of respite care? Once again, these situations will vary from program to program, but this is the time to familiarize your trainees with all procedures elsewhere in the training. Go over all the forms with the group and have them practice filling them out.



## COMPETENCY ASSESSMENT

**PURPOSE:** To measure the trainee's common sense and ability to deal with the consumer family and client on a personal level.

To allow the trainee to demonstrate an overall competency of procedures studied during the training session.

**METHOD:** Written assessment exercise

**MATERIALS:** Pencil and one copy of assessment exercise for each trainee

**TIME:** 45 minutes

### Notes to the Coordinator

At the conclusion of training, you may wish to get a written check on the competency of the trainees. The following assessment device was developed to measure the trainee's common sense and ability to deal with the client and the family on a personal level. This exercise is not content-oriented (it does not contain specific questions that have specific right and wrong answers). Instead, the questions allow the trainee to demonstrate his/her ability to evaluate and assess certain situations which might arise in a respite care setting. Before administering this assessment, the trainer should consider what level of competency the trainee should possess before he/she begins to provide respite services. But, this assessment should *not* be used as the sole determiner; whether or not a person should be used should be based upon the trainee's performance during training, his/her references, past experiences, character evaluation, and the results of this assessment.

Just as this assessment has no "correct" answers, it also has no strict guideline as to the percentage of responses needed to "pass" this exercise. The trainer must determine the prerequisite skills necessary for someone to provide respite care.

This assessment could be introduced in the following manner:

Trainer: "You will now be given a series of situations that could occur while you are providing respite care. After each question is a space in which you are to write your answers. They need not be too long (usually two or three sentences will suffice), and there are no single correct answers to these questions. Several answers may be acceptable. This assessment is *not* intended to be an exam, but it is just one of several measures I need to evaluate your ability to provide respite care. Some of the material will be based on topics that we discussed during the training. Other items are geared to assess your "common sense" or ability to "think on your feet." You should need about 45 minutes to complete this task. If you have any questions, please feel free to raise your hand during the exercise, and I will try to help.

Note that no mention was made of this being a "test." By using the words assesment and exercise, you are further reinforcing the concept that this is only one of several criteria that you will be using to judge the trainee's ability to be a good respite care provider.

A set of sample assessment questions follows, and the proper answer areas are given for each situation. You may use this assessment, or you may wish to compile a list of questions that apply more directly to your program. NOTE: If you use the sample assessment, you will have to blank out the "Looking-for" answers when you duplicate the set of questions.

NAME: \_\_\_\_\_

1. The respite care client is running a temperature of 102.5. What procedures might you follow?

Looking For: Basic Knowledge of Health Care.

2. The client has already eaten three bowls of ice cream. What might you do if he/she insists on having more?

Looking For: Behavior Management.

3. A stranger comes to the door and says he is a friend of Mr. Smith, the father of your client. Mr. Smith will not be home for another hour, but the friend says he will wait. What might you do or say?

Looking For: Trainee's sense of good judgement.

4. When you arrive at the Jones home to provide respite care, the Jones family is surprised to find that you are a member of a different race than they. What might you say to them?

Looking For: Trainees's sense of tact and confidence.

5. Mrs. Roberts tells you that you must remove John's hearing aid before he goes to bed, but you have never seen that type of hearing aid. What might you do?

Looking For: Interviewing technique-"show me approach."

6. Your client has gotten into the medicine cabinet and appears to have eaten a handful of pills; the bottle is open, and there are several pills on the floor. What might you do?

Looking For: Knowledge of health, quick reaction, poison control, etc.

7. While providing respite care, a friend of yours comes by to visit. The client is asleep. What might you do?

Looking For: Trainee responsibility.

8. A half hour after the Miller family leaves to visit a friend's home, they return with the friend's handicapped child. They suggest that while you are watching their child, you should also watch their friend's child. What might you do?

Looking For: Knowledge of agency procedures and tact.

9. You are providing overnight respite care, but during the early morning you find that you have become ill, and you are running a high fever. What might you do?

Looking For: Trainee judgement and basic medical knowledge.

10. By mistake, you have given Bobby one tablespoon of his cough medicine rather than one teaspoon. What might you do?

Looking For: Responsibility and medical knowledge.

11. Although Jane's bedtime is 8 o'clock, at 9:30 she continues to remain awake in her bed singing songs. What might you do?

Looking For: Behavior management.

12. You are providing respite care and after the relative of the client has left, you realize that you must make a long distance telephone call. What should you do?

Looking For: Good judgement.

13. You have just been called by the respite coordinator, and you have agreed to provide respite care for tomorrow evening. An hour after you agreed to provide the service, you realize that the home is in a neighborhood that you are frightened to enter. What would you do?

Looking For: Knowledge of agency policy and responsibility.

14. James, your client, is extremely shy and has refused to come out of his bedroom. After an hour of ignoring this behavior, you become concerned. How might you get James to come out of his bedroom and interact with you?

Looking For: Behavior management and client-provider relationship building.

15. Sheila has several grand mal seizures within an hour of her parent's departure for the weekend. She generally has only one seizure per month, so this pattern is unusual. What might you do?

Looking For: Medical knowledge and responsibility.

16. Tom's parents have left for their first outing in several years. They proceed to call you every fifteen minutes to check on Tom's safety. After the fourth call, you feel it would be helpful to everyone, including Tom who wakes up each time the phone rings, if his parents stop calling. How might you get the parents to stop and feel comfortable about doing so?

Looking For: Client relative-trainee relationship building and confidence.

17. Patty cannot speak but is able to communicate with sign language. You know only a few signs. During the night, she awakens quite upset and begins frantically to sign something that you do not understand. What might you do?

Looking For: Client-provider relationship, communication skills.

18. Timothy has gone to the bathroom and has been in there for 15 minutes. When checking to see if there is any problem, you notice water coming out from under the bathroom door. When you enter the room, you find the toilet overflowing. What might you do?

Looking For: Provider common sense.

19. Sharon is a fourteen-year-old girl with limited vision. After her parents have gone for the evening, several of her friends from school arrive and say they are here for Sharon's party. Her parents made no mention of a party in their explicit instructions to you. What might you do?

Looking For: Client-provider relationship, and provider responsibility.

20. Sandy, a six-year-old client, has just been caught taking some change out of your coat pocket. What might you do?

Looking For: Behavior management and client-provider relationship.

21. Jerry's parents have warned you that he has some serious behavior problems for a ten-year-old boy, and he will do nearly anything for a joke. After he has gone up to bed and has apparently been asleep for an hour, the police arrive and say they have just received a call that there was a murder at this address. Jerry is sitting at the top of the stairs laughing. What might you do?

Looking For: Behavior management and client-provider relationship.

22. Mr. Kane said that she would need respite care for four hours. She returns in a half hour and says she changed her mind and asks you to leave. Since you were promised four hours' work, you are upset. What might you do?

Looking For: Client relative-provider relationship, and knowledge of agency policy.

23. Mr. Hayes tells you that his son Darrel is to receive 4 grams of medication X before bed. You don't know how to measure 4 grams. What might you do?

Looking For: Interview skill and basic medical knowledge.

24. Carolyn's parents have told you that they always read a bedtime story of her choice each night. At bedtime, Carolyn insists that you read her Volume 6 of the encyclopedia. This book has over 600 pages. What might you do?

Looking For: Behavior management, and client-provider relationship.

25. Lucinda has just eaten all the leaves of her mother's Swedish Ivy plant. What should you do?

Looking For: Quick reaction, and knowledge of health care.

(HANDOUT)

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